ANGLIA RUSKIN UNIVERSITY

FACULTY OF ARTS, LAW AND SOCIAL SCIENCES

AN INVESTIGATION INTO THE LINKS BETWEEN MUSIC THERAPY FOR ADULTS WITH LEARNING DISABILITIES WHO SELF-HARM AND STAFF SUPPORT GROUPS FOR THEIR CARERS

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ABSTRACT

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This qualitative study investigates the use of music therapy for adults with learning disabilities who self-harm. It also considers the role of their care staff in responding to self-harm. Studies in this area acknowledge that self-harm is complex for those engaging in it and their staff teams. Recommendations from studies with staff teams working in this area conclude that staff are asking for more support. Studies show that service-users are requesting access to therapy.

This research project investigates two service-users and their staff teams in detail. Music therapy was offered to the service-users for one year, providing the opportunity to process experiences through language and improvised music. Care staff participated in a monthly group that offered space to explore their experiences of supporting somebody who self-harms. Data was gathered through semi-structured interviews administered to participants at the start of the study, and twice more at six-monthly intervals. The interviews were transcribed and analysed within a framework of interpretative phenomenological analysis.

The study investigates a possible correlation between this combined approach and a reduction in self-harming for the service-users and a change in how staff understood self-harm and responded to it. Results support a positive correlation between these interventions and a reduction in incidences of self-harm among service-users, as well as a change in the responses of their care staff. Service-users linked the opportunity to express difficult emotions through music therapy to a reduction in self-harming. Staff teams reported benefits of attending the groups and came to new ways of understanding their service-users.

As a result of this study, music and art therapy groups for the staff teams of adults with learning disabilities are being developed and trialled within the NHS trust in which this study took place. This work is being carried out alongside clinical interventions for service-users, resulting in a systemic approach that attends to service-users and staff teams simultaneously.

Key words: music therapy, learning disability, self-harm, carers, groups

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LIST OF ABBREVIATIONS

A&E:	Accident and Emergency
AMPH:	Approved Mental Health Professional
APMT:	Association for Professional Music Therapists
ASD:	Autistic Spectrum Disorder
BAMT:	British Association of Music Therapy
BILD:	British Institute of Learning Disabilities
BSMT:	British Society for Music Therapy
DSH:	Deliberate Self-Harm
GAM:	Group Analytic Matrix
HCPC:	Health and Care Professions Council
HRA:	Health Research Authority
IPA:	Interpretative Phenomenological Analysis
IQ:	Intelligence Quotient
IRAS:	Integrated Research Application System
MDT:	Multi-Disciplinary Team
NHS:	National Health Service
NICE:	National Institute of Health and Care Excellence
PRI:	Perceptual Reasoning Index
PSI:	Processing Speed Index
REC:	Research Ethics Committee
SBV:	School Board Visitor
SGF:	Staff Group Facilitator
SIB:	Self-injurious behaviour
SSI:	Semi-structured interview
VCI:	Verbal Comprehension Index
WAIS:	Wechsler Adult Intelligence Scale
WMI:	Working Memory Index

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MARCH 2019

Chapter 1: Situating the Inquiry

Go, go, go said the bird: human kind
Cannot bear very much reality.
Time past and time future
What might have been and what has been
Point to one end, which is always present…

T.S. Eliot

The consideration of self-harming amongst the learning-disabled population might be an uncomfortable subject, a reality that is hard to bear. Yet for some people with a learning disability, self-harming is a significant part of their experience. People with learning disabilities are less likely to be invited to participate in research than those without learning disabilities, their voices less well represented and heard (Gilbert, 2004; Durell, 2016). This study investigates the use of music therapy with adults with learning disabilities who self-harm. It also considers the role of care staff in responding to self-harm: it examines their perceptions and understanding of what an act of self-harm might mean and how this determines their response to it. By offering weekly music therapy to the service-user and a monthly group for care staff, which allows the staff team to explore their experiences of supporting someone who self-harms, the study examines whether this combined approach correlates to a reduction in the number of incidences of self-harm for the service-user and a change in how the care staff might understand and respond to self-harm when it does occur.

1.1 Context

In the UK, since the closure of long stay institutions and the resettlement of learning-disabled people into the community, it has become the tradition for many adults with learning disabilities to live in a group home. They might live with several other people and are likely to be supported by a team of care staff on a rotational basis. Care staff are expected to support people who may have had traumatic histories and may have subsequently developed complex, unconscious psychological structures in order to

manage and defend against their experiences. Due to their learning disability, service-users may have limited ways of communicating their experiences, instead resorting to challenging behaviours, including self-harm, to manage unbearable emotional states. Given these complexities, it is striking that there is often very little investment in training and supervision for support staff responding to somebody who harms him/herself. It seems to be the case that a lack of financial investment and incentive for care staff means that group homes often attract staff who are young and unqualified. Multi-disciplinary teams (MDTs), explained in §1.2, can sometimes be quick to condemn what might seem to be inappropriate responses from care staff towards people who self-harm; yet very often, staff are not offered the resources they may want or need to enable a different kind of response to be possible.

1.2 Personal motivation

My clinical practice has taken place within a Mental Health NHS Trust in the UK. Since I joined the Trust in 1996, adults with learning disabilities have been resettled from living in a long-stay institution to living in the community, with the greater independence and freedom of choice that community living affords. The structure of the MDTs has also changed considerably during this time. When I first joined the service, clinicians were in departments with colleagues of the same discipline; now the emphasis is on the multi-disciplinary health and social care teams where people can be thought about in broader, more holistic terms and with a greater diversity of perspective and flexibility. The MDT is part of a wider service that attends to the health and social care needs of adults with learning disabilities. The MDT consists of social workers, care managers and the following health professionals: learning disability nurses, a health care assistant, psychiatrist, psychologist, speech and language therapist, occupational therapist, physiotherapist, music therapist, art therapist, team manager and administrative staff.

My interest in people with learning disabilities who self-harm and the role that care staff play in supporting them has arisen from an increase in these referrals to our MDT. By the time someone is referred because of an exacerbation in their self-harming, the staff

team is usually finding the situation extremely difficult to manage. Frequently splits and divisions within the staff team occur as staff may unconsciously 'compete' to find the best way of dealing with the situation. The nature of self-harm can quickly put us in touch with feelings of inadequacy and powerlessness, as can learning disability itself, and these feelings can become played out within the staff team and between carer and service-user in complicated struggles about power and control.

Self-harm often brings with it a sense of emergency and crisis which can feel exhausting for staff teams and clinicians. It is particularly noticeable that service-users who self-harm often remain known to MDTs for many years and may have seen a number of clinicians in that time. As an MDT, we have become increasingly interested in the different ways in which members of staff within a single staff team respond to a service-user who self-harms and the ways in which staff's own views and life experiences shape their opinion about how self-harm can be understood and responded to. It became clear that for some service-users, the lack of a cohesive and consistent approach from staff when they did harm themselves was maintaining or creating particular difficulties as well as leaving staff unsure about how they should respond. We observed an increase in staff teams approaching our service for support for themselves as well as for the service-users they were caring for.

1.3 Situating the inquiry

There is much evidence to suggest that supporting service-users who self-harm has a considerable emotional impact on care staff; staff teams trying to support people who self-harm often experience greater feelings of guilt, anger and hopelessness than staff supporting service-users with other types of challenging behaviour (British Institute of Learning Disabilities (BILD), 2011; Gibb, Beautrais and Surgenor, 2010). The staff teams who were known to our MDT described a range of feelings which included feeling powerless, guilty (for not being able to prevent the self-harm), angry with the service-user and unsure of how to manage the situation or prevent further episodes of self-harm. Frequently staff described feeling hopeless. The task of supporting somebody who self-harms usually has to take its place alongside the support needs of

several other service-users living in the same home and often the staff we encountered were struggling to meet the different needs of a diverse population.

A study by Dick et al. (2011) and commissioned by the British Institute of Learning Disabilities (BILD), explored staff beliefs about why people with learning disabilities self-harm. This study will be discussed more thoroughly in §2.8. Staff's perceptions of self-harm were shown to correlate to the quality of care they offered to their service-users. The conclusions from the study were that staff would welcome further support and would like to increase their understanding of the complexities arising from supporting service-users who self-harm. A means of expressing the tensions arising from supporting these service-users was also one of the recommendations. By offering a staff support group alongside weekly music therapy for the service-user, I want to investigate whether this combined approach that also attends to the staff team, correlates to any reduction in self-harm. This research study will consider what meaningful support can be offered to staff to enhance understanding and support improved relationships between service-users and support staff.

The experiences of care staff working with patients who self-harm within a forensic learning disability service were investigated by Fish (2000); the author concluded that staff felt relationships with patients were sometimes hostile and involved issues of power struggles, boundaries, risk and control. The studies by Fish and BILD make recommendations for further research into ways of supporting staff teams and suggest that staff teams would like better information about the nature of self-harm and how to respond to it.

The weekly, individual music therapy intervention for the service-users in this study, offers a non-verbal, psychotherapeutic encounter in which feelings can be expressed and acknowledged through both verbal and improvised musical exchanges. Through this medium the therapist seeks to understand something of the service-users' unconscious emotional world. Reasons for self-harm can be explored within a safe and supportive therapeutic environment. An extensive literature search has found very little research about the effects of music therapy on adults with learning disabilities who self-

harm in terms of a specific reduction in self-harming. Brown and Kimball (2013) state that, 'despite growing prevalence rates, researchers have yet to adequately address the treatment needs of those engaging in the [self-harming] behaviour. Relatively no data are available regarding empirically based preventions or interventions (Prinstein, 2008) and no empirically supported treatments are available to reduce self-harming behaviour' (Brown and Kimball, 2013, p. 195).

1.4 Background to this research study

My interest in researching this area arose through an increasing number of referrals to our MDT for people with a chronic history of self-harm. My colleagues and I began to make several observations about the nature of the referrals we were receiving and certain commonalities began to evolve. It became clear that the same people were repeatedly referred and frequently to a number of disciplines in an exhaustive attempt to find something that would stop the self-harming behaviour. Staff were often demoralised and tired; episodes of self-harm could be dramatic, often requiring lengthy trips to hospital and long waits in accident and emergency departments for treatment. It is not uncommon for staff to have spent much of the night in hospital with the service-user that they support, having worked beyond the requirements of their shift pattern. Care staff often contacted our team at a time of crisis, usually when the service-user had self-harmed in a way that had caused significant damage, sometimes necessitating the involvement of the police and/or hospital services. These referrals were often characterised by panic and a sense of emergency; as a team we became interested in how we could respond to these situations and referrals in a calm, thoughtful way, without being drawn into the drama and anxiety that often surrounded them.

1.5 Background study

Before this PhD study was designed and submitted for ethics approval, I had been involved in an informal clinical project which ultimately led on to this research. Among the increasing number of referrals of people with a chronic history of self-harm to our team, we received a referral of a young service-user with learning disabilities, a

personality disorder and a forensic history. The person lived in supported living accommodation (with other people with learning disabilities and a full-time staff team) and had a chronic history of self-harm. The staff were finding it difficult to respond to an increasing number of incidences of self-harm which saw frequent trips to accident and emergency departments and regular police involvement. Our team became involved with the service-user and the staff team and began to consider how best to support them both. We started to consider different ways of thinking about how we might work with the staff team and the potential impact of this upon any therapeutic work that was offered to the service-user. There were frequent emergencies due to the service-user's self-harming and meetings with health professionals and care staff, known as strategy meetings, were often convened quickly to try to respond to the latest developments. Staff were understandably anxious and these meetings were often quite emotionally heightened. Sometimes it felt difficult for us, as a health team, to adequately contain the staff's anxieties and provide something helpful. An art therapy colleague, our team psychiatrist and myself became interested in the idea of holding a regular scheduled meeting for the staff team that was not dependent on a crisis or scrambled together in a hurry. The idea of offering this was to see whether the care staff might feel more listened to and supported by a regular meeting and to ultimately see whether or not this might help to ameliorate the current situation that the staff team was experiencing. The service-user continued to have individual weekly therapy sessions and the staff were offered a monthly group for six months. As many staff as were available attended the group sessions and it provided an opportunity and a space for staff to reflect on how things had been during the previous month and talk about any incidents that had been difficult to manage. We were struck by how quickly staff committed to the group and how readily and honestly they engaged with us about their experiences. They seemed to welcome the opportunity to think and talk and were very open about the wider difficulties within the service in which they worked. These difficulties included a lack of supervision and an absence of any training about dealing with self-harm and other challenging behaviours. We soon gained a sense of the low morale that was prevalent within the staff team: people felt underpaid and undervalued and there was little investment in training or in equipping the staff to deal with some of the more distressing behaviours that the service-user they were supporting sometimes

displayed. These behaviours included self-harm, physical and verbal aggression and were within a context of childhood abuse. As the groups progressed, staff reported feeling more confident in dealing with any difficulties involving the service-user, particular any behaviours that might precede an episode of self-harm; they also noted that the frequency of self-harming had lessened significantly. All staff reported an improvement in their relationship with the service-user and felt more empowered in dealing with episodes of self-harm when they did occur. In particular there was a significant reduction in the number of emergencies and therefore the need for hastily arranged strategy meetings. Although evidence that this model of working might be useful was purely speculative and anecdotal at this stage, it seemed significant enough to be deserving of further investigation. This is how this research project came about.

1.6 A brief introduction to the study

This qualitative first-person single case study design is with adults with mild-moderate learning disabilities, who regularly self-harm. The study lasted for one year. I investigated the combined approach of weekly music therapy sessions for the service-user, with its opportunities for musical and non-verbal therapeutic engagement, alongside a monthly staff support group for the care staff who were supporting the service-users. Also investigated was an analysis of changes in the staff's perception and response to the self-harming. Links were explored between any reduction in the incidents of self-harm and changes in staff perception during this period. Semi-structured interviews were carried out with service-users and staff prior to the start of music therapy treatment, and measurements were taken to determine the frequency of self-harming throughout the study.

Chapter 1 has situated the inquiry, offering a context for the research and describing my motivation for undertaking this research. It has described an informal study that I undertook with colleagues which helped to shape and define the research questions that form the basis for this thesis.

Chapter 2 offers a historical overview of music therapy, learning disabilities and self-harm, incorporating a thorough review of the literature. It discusses some of the important Acts to be passed and the impact these have had upon people with learning disabilities.

Chapter 3 describes the methodology and discusses the research design and research questions that arose as a result of the literature review. The chapter discusses the rationale for choosing a qualitative design and for analysing the data through an Interpretative Phenomenological Analysis framework.

Chapter 4 discusses the methods used for conducting this research study. The study design and methods of recruitment are described here as well as the processes for administering the SSIs and gathering the data. The methods for conducting the music therapy sessions and the staff groups are also explained.

Chapter 5 demonstrates the process by which the data was gathered through the analysis of two case studies. Highlighting the clinical processes of music therapy for the two participants and the monthly staff groups for the staff teams, this chapter illustrates the parallels between the themes that emerged in those two domains of work.

Chapter 6 presents the results and a synthesis of the themes that emerged in the individual participants and their staff teams. A master table of analysis shows the distillation of themes.

Chapter 7 describes how the study has answered the research questions. It summarises the main findings and discusses these within the context of the current literature. The method, study design, data collection and analysis are also discussed here.

Chapter 8 reflects on how this study contributes to knowledge and the impact of this research so far. It suggests recommendations for future research and discusses the implications for clinical practice and music therapy training.

1.7 A word about terminology

Throughout this study I refer to people, or adults with learning disabilities that self-harm. The literature review has revealed differences in terminology which may correspond to the country that the work was undertaken in, as well as historical context. The terms 'developmental disabilities', 'intellectual disabilities', 'learning disabilities', 'learning difficulties', 'mental handicap' and 'mental retardation' can all be found in the literature. Currently the UK favours the term 'learning disabilities' and both participants in this study identify as having a learning disability. I then considered whether it is acceptable to refer to somebody with a learning disability as 'learning-disabled'; again both terms, 'learning-disabled' and 'person with a learning disability' are regularly used within current literature. I discussed this with the two participants in this study and both said that they found either term acceptable. I have interchanged these terms throughout this thesis in order to reflect the preferences of the service-users taking part in this study and to ensure that both terms are represented.

The terms 'self-harm', 'self-injury' and 'self-injurious behaviour' are also all found within the current literature. This is discussed in §2.6.1. For the purposes of this study I have chosen to use the term 'self-harm', reflecting, as I think it does, the broader implications of harm and distress that go beyond the physical manifestation of the injury.

Please note that during this research study my surname has changed from Hind to Ogilvie.

Chapter 2: An Overview of Music Therapy, Learning Disabilities and Self-Harm

2.1 Introduction

This chapter begins by giving a definition of music therapy with some history of its roots in the ancient world, its resonances to literature and art, through to its more recent evolvement in the UK. There will then follow a consideration of the literature about music therapy and adults with learning disabilities until the end of 2017. Following this will be a review of self-harm. This will include a discussion about how self-harm might be defined and will give an overview of its prevalence within mainstream society and then, more specifically, within the fields of mental health and learning disabilities. I will then consider what is meant by the term 'learning disability'; different categories of learning disability will be explored here. This chapter will also include a history of learning disabilities in §2.5.2 and will describe important developments in legislation. I will then consider self-harm and learning disability together. Section 2.7 considers music therapy within the historical context of a long-stay institution and how music therapy provision has changed since care in the community came into being. The review will then address the issue of carers and their role in supporting people with learning disabilities; the experiences of carers supporting people with learning disabilities who self-harm will be explored. Finally the review will consider the views of people with learning disabilities who engage in self-harm. Through exploring each of these areas in turn, gaps in the literature will be revealed which this research study seeks to address.

For each section of this literature review, papers, conference proceedings, books and online journals were investigated. Searches combined the following terms: 'music therapy', 'music therapy + learning disability', ' music therapy + learning difficulties', 'music therapy + intellectual disabilities', 'music therapy + developmental disabilities', 'music therapy + challenging behaviour', 'music therapy + staff teams', 'music therapy + care staff', 'music therapy + self-harm', 'music therapy + groups', 'care staff + self-

harm', 'care staff + self-injury', 'self-harm + self-injury', 'self-injurious behaviour', 'care staff + learning disability', 'learning disability + groups', 'learning disability + self-injury' and 'learning disability + self-harm'.

Sources consulted online include:

- Google Scholar
- Wiley Library
- Conference proceedings
- Journal of Applied Research in Intellectual Disabilities (known as Mental Handicap Research from 1988–1995)
- Developmental Disabilities Research Reviews (known as Mental Retardation and Developmental Disabilities Review from 1995–2007)
- British Journal of Learning Disabilities
- Journal of Intellectual Disability Research (JIDR)
- British Journal of Music Therapy
- Canadian Journal of Music Therapy
- Australian Journal of Music Therapy
- Nordic Journal of Music Therapy
- Anglia Ruskin online library resource
- British Library

2.2 What is music therapy?

Music therapy recognises that we are born with innate musical tendencies. It also acknowledges that we all live rich lives that contain both good and bad experiences. This allows us to recognise two things: that, regardless of disability or illness, all human beings experience the same vicissitudes of mood and range of emotional experience; that we are all subject to similar drives and desires and these are not impaired by disability. Yet sometimes people with learning disabilities may have limited means through which to communicate aspects of their emotional life, or to share their thoughts, ideas and desires with other people. When this shared understanding is not possible, there may be significant implications for a person's feeling of self-worth and sense of

self. Music therapy seeks to understand this by ascribing meaning and significance to every sound and silence that the patient brings to the therapeutic encounter. In responding to these sounds and silences with their own, the music therapist can invite the patient into a meaningful and creative therapeutic relationship where the patient's communications can be shared, ascribed meaning to and understood.

The notion that we are all born as intrinsically musical beings is the basis of Malloch and Trevarthen's book (2009) *Communicative Musicality: Exploring the Basis of Human Companionship.* In it, the authors explore the musical nature of mother-infant interaction and describe studies in this area that have revealed noticeable patterns of melodic gesture, timing and vocal timbre consistent with the rules of musical performance.

The British Association of Music Therapy (BAMT) also describes the universal ability to respond to music and says that this connection that humans have to music allows positive changes to take place in terms of emotional well-being, through the use of shared, improvised music between the patient and the therapist:

> Central to how music therapy works is the therapeutic relationship that is established and developed through engagement in live musical interaction and play between a therapist and client. A wide range of musical styles and instruments can be used, including the voice, and the music is often improvised. Using music in this way enables clients to create their own unique musical language in which to explore and connect with the world and express themselves.
>
> (BAMT, 2017)

Music therapy sessions take place at the same time each week, with the same music therapist and in the same room. Considering the complex and often distressing feelings that might arise during a music therapy encounter, adherence to this framework around the music therapy gives a feeling of familiarity, consistency and safety to the patient, allowing difficult feelings to be better tolerated and contained. The room would ideally be comfortable, quiet and private, with chairs for both patient and music therapist and a range of tuned and untuned percussion instruments arranged around the room. This would represent the optimal environment, but often music therapists and service-users have to work within a less than ideal environment. Music therapists are interested in the

instruments chosen by the patient and attend to the ways in which the instruments are played and used. Such matters are considered as a communication from the patient about their emotional world and their capacity to share that with the therapist. In turn, the therapist seeks to recognise, receive, acknowledge and respond to these communications through his or her own musical responses. His/her music might seek to reflect back certain aspects of the patient's playing — a rhythmic idea or a melodic motif — thus enabling the patient to feel recognised. At other times, the therapist might invite the patient to develop their music by expanding, extemporising and generating new musical ideas to see whether the patient is able to make use of them to augment their own musical communications. Music therapists work with a broad range of people including: mothers and babies, children and young adults with learning disabilities or mental health problems, adults with a mental illness, people within the prison system, older people, those with dementia, those people who have had strokes or head-injuries, people who have been abused, endured trauma and those receiving end of life care.

Music therapy first came to prominence in the UK when Juliette Alvin and her colleagues founded the 'Society for Music Therapy and Remedial Music' which later became 'The British Society for Music Therapy', a registered charity which Alvin founded in 1958. Its purpose was to promote the use and development of music therapy. Although music therapy was very much an emerging profession in 1958, the healing properties and benefits of music date back thousands of years.

2.2.1 The ancient roots of music therapy

The Greek god Apollo was an important and complex god of many things, including the sun, light, knowledge, medicine, healing, music, art and poetry. He was the first god to be associated with both music and medicine. This connection between music and medicine continued through his son, Asclepius. He was also a god of medicine and healing in ancient Greek mythology and religion. He named his daughters Hygieia ('Hygiene', the goddess of health, cleanliness, and sanitation), Iaso (the goddess of recuperation from illness), Aceso (the goddess of the healing process), Aglæa/Ægle (the goddess of the glow of good health), and Panacea (the goddess of universal remedy).

Asclepius became a proficient healer, evading death and bringing others back from near deadly illnesses. He was also supposed to have cured diseases of the mind by using song and music. References to Asclepius and his daughters can be found in the original Hippocratic Oath which began:

'I swear by Apollo the physician and by Asclepius and by Hygieia and Panacea and by all the gods…'

(Hippocrates 460-370 BC)
(oath thought to have been written between the fifth and third centuries AD)

Writing about Hippocrates and health care practices in ancient Greece, Kleisiaris, Sfakianakis and Papathanasiou state that:

'Mental care and art therapy interventions were in accordance with the first classification of mental disorders, which was proposed by Hippocrates. In this category music and drama were used as management tools in the treatment of illness and in the improvement of human behavior.'

(Kleisiaris et al., 2014, p. 1)

2.2.2 Robert Burton and *The Anatomy of Melancholy*

Evidence of the elevated status of music can be found in the written genre also. Written in the seventeenth century, Robert Burton's book, *The Anatomy of Melancholy*, seems, at first glance, to be a treatise on the subject of melancholia, or what might be described today as clinical depression. He describes the pervasiveness of melancholy in all people, satirically writing in his preface that: 'I write of melancholy by being busy to avoid melancholy' (Burton, 1621, preface). The book draws on a wide range of techniques of the day for treating melancholy including psychology, physiology, astronomy, meteorology, astrology and theology, but as the quotation below shows, he describes music as a 'sovereign remedy':

'But to leave all declamatory speeches in praise of divine music, I will confine myself to my proper subject: besides that excellent power it hath to expel many other diseases, it is a sovereign remedy against despair and melancholy, and will drive away the devil himself.'

(Burton, 1621, §2.2.6.3)

2.2.3 Louis Gallait: *The Power of Music*

The healing power of music, articulated across the arts in ancient Greece, was, centuries later, represented in a painting by Louis Gallait (1810–1887). A Belgian painter, Gallait was part of the impetus for a revival of history painting in Belgium. One of his well known paintings, *The Power of Music* (Figure 2.1), depicts a brother and sister resting on an old tomb. In a letter written by the artist to William Walters, dated 20th July 1860, Gallait describes the brother trying to comfort his sister by playing the violin to her. She has fallen into a deep sleep 'oblivious of all grief, mental and physical' (Gallait).

Fig. 2.1: The Power of Music (1852) by Louis Gallait (1810–1887)

2.2.4 Modern development of music therapy

In the early twentieth century, music was used in hospitals after both World Wars as part of a programme of treatment for soldiers recovering from the traumatic effects of witnessing active service. Music therapy came to greater prominence in the UK in the

1950s–1970s when it was pioneered by Juliette Alvin. Music therapy began to divide into two distinct branches: the more improvisatory, musical and analytic tradition as pioneered by Mary Priestley, Alvin's student; and the creative music therapy approach as developed by Nordoff and Robbins in the 1950s and 1960s.

Whilst both approaches are united by placing music at the heart of the clinical encounter, they differ in important ways. The creative music therapy approach focuses on the idea of music as an agent of therapeutic change in itself; the more analytic or psychodynamic way of thinking takes into account the therapeutic relationship between patient and therapist and considers this, along with the music, to be the agent for therapeutic change. Psychoanalytic theory is often used to inform practice in a psychodynamic model of music therapy practice (Odell-Miller and Darnley-Smith, 2001).

2.2.5 Governing bodies and registration for music therapists in the UK

In April 2011, BAMT took over from the British Society for Music Therapy (BSMT) which had been established by Juliette Alvin in 1958. The BSMT was open to anyone with an interest in music therapy and did much to bring music therapy into the public domain. BAMT brought together the BSMT and the Association for Professional Music Therapists (APMT), the main UK music therapy organisation for qualified and trainee music therapists. The APMT campaigned for an international reputation for excellence in music therapy practice and research and achieved state registration for music therapists in 1999. As a result of this, all practising music therapists, as part of the larger body of Allied Health Professionals, or AHPs, are now required to be registered with the Health and Care Professions Council (HCPC). The HCPC is a regulatory body, designed to protect the public by ensuring that all practitioners on its registers meet stringent standards for professional development, training, skills, behaviour and health.

2.3 Music therapy and people with learning disabilities

The practice of music therapy with people with learning disabilities is well established. Early documented work in this clinical field in the UK can be found in articles by Toolan and Coleman (1994), Lawes and Woodcock (1995) and Oldfield and Adams (1990). The following section will discuss the use of music with learning-disabled people, as distinct from music therapy, followed by a historical overview of music therapy and adults with learning disabilities both in the UK and internationally. The review of the literature extends until the end of 2017. Any new literature since then will be discussed in §8.4.

2.3.1 The use of music with people with learning disabilities

In his book, *Music and People with Developmental Disabilities*, Schalkwijk (1994) gives an overview of how music has been used as a way of caring for the adult learning-disabled population. The book is, in part, a distillation of his PhD thesis which investigated how music therapists worked with adults with learning disabilities in different clinical settings in the Netherlands. An important distinction exists between the use of music with people with learning disabilities and music therapy, which Schalkwijk addresses in his book. He explains some of the ways in which music was used across the Netherlands and America at the end of the 1960s, including a focus on the use of music to facilitate the learning of certain facts such as using song to learn the days of the week or certain skills. Jackson (2007), working in Ireland, investigated the use of music activities that were initiated by staff for people with learning disabilities. The research revealed that 90% of the participants in the study (carers, non-music therapists, learning disability professionals and family members) felt that their service-users (adults with intellectual disabilities) benefitted from engagement in musical activities. Positive results were shown in the areas of improved mood and greater interaction with peers and staff. The use of music was contrasted with other, non-musical interventions, with the study revealing that 90% of participants felt that music was either equal to, or more effective than other interventions.

2.3.2 Early pioneers of music therapy with learning-disabled adults

In the 1950s and 1960s musicians across the world were beginning to work with children and adults with learning disabilities, thereby sowing the early seeds of music therapy. These included Juliette Alvin in the UK, Paul Nordoff and Clive Robbins and Edith Boxill in the US.

2.3.3 Alvin's cello

In her seminal book, *Music Therapy,* first published in 1966, Alvin describes the effects of playing her cello to handicapped children. The book contains photos, including a blind child crawling towards the source of the sound, i.e. Alvin's cello, with another child nearby reaching out to pluck a string. Alvin was interested in the effects of music upon illness and the ways in which music allowed people with disabilities to find new ways of relating to others beyond the limitations of their disability. She cites a story of a young pupil who she describes as being *'saved from serious maladjustment by learning the cello at the right moment and with the right motivation'* (Alvin, 1966, p. 101). The pupil lacked musical ability and Alvin discovered him to be shy, lonely and anti-social. His ambition to learn a well known piece of cello music, and the strength of the relationship that developed between him and Alvin, allowed him to persevere to the stage that he was able to join a school orchestra. Through this he found acceptance and a new way of belonging; this correlated to an improvement in his anti-social behaviour as well as his academic studies. Alvin also documents the benefits of music for adults in a social context, alleviating loneliness and social isolation:

> 'Musical activities and experiences can help people who feel deprived, lonely and in danger of becoming withdrawn…they can find, in music, an opportunity to…express themselves and to share.'
>
> (Alvin 1966, p. 101)

She also makes reference to adults with a variety of physical and learning disabilities, making particular acknowledgement of the role of playing music in addressing physical difficulties arising from paralysis and other manifestations of physical disability.

2.3.4 Paul Nordoff and Clive Robbins

During the late 1950s and 1960s in America, Paul Nordoff and Clive Robbins were also experimenting with using music in day centres and schools for people with learning disabilities. Paul Nordoff, an American composer and pianist, and Clive Robbins, a special educational needs teacher, developed a way of collaborative music making to engage vulnerable children and those with physical and learning disabilities. Their work made significant findings in terms of developing self-control, concentration and social awareness. They continued developing and researching their work throughout the 1960s and their first UK service was developed by Sybil Beresford-Pierse in 1970. A UK training course followed four years later and their work continues to grow and develop with Nordoff Robbins music therapy centres across the world, offering training and music therapy to people of all ages encountering disabilities, illness and difficult circumstances.

2.3.5 Edith Boxill

Born in Providence, Rhode Island in 1916, Edith Boxill became known as a music educator, composer, performer and music therapist. Another early pioneer of music therapy with people with learning disabilities, she became Director of the Manhattan Development Center from 1974, before becoming Professor of the New York University Music Therapy department from 1980. Her book, *Music Therapy for the Developmentally Disabled* (Boxill, 1984), is accompanied by a recording of twelve songs, selected for creating an experience that was rooted in music and movement, sensory-motor experience, chanting and singing.

2.3.6 Music therapy case studies with learning-disabled adults: 1980s–1990s

Tessa Watson's book, *Music Therapy with Adults with Learning Disabilities* (Watson, 2007), gives a thorough overview of the development of music therapy in the UK with this client group. The earliest examples of documented work by music therapists working with adults with learning disabilities are mostly to be found in books and

journals. Case studies by Zallik (1987), Cowan (1989), Gale (1989), Ritchie (1991), Clough (1992) and Sobey (1993) are documented in the British Journal of Music Therapy. As work continued to advance in the area of music therapy with learning-disabled adults, different theoretical frameworks were developing, including a more psychoanalytic framework in which to consider music therapy with this client group. Prevailing changes in attitude towards adults with learning disabilities allowed for a greater acknowledgement of the past traumas and complexities of life that some learning-disabled people had experienced. In addition to these changes in perspective, greater emphasis was placed on people with learning disabilities having better access to the opportunities for choice that people without disabilities may take for granted. Some of the case studies mentioned were already framed within a psychoanalytically informed context. Christopher Gale in his paper entitled *'The Question of Music Therapy with Mentally Handicapped Adults'* (Gale 1989), discusses 'normal' and 'segregated' activities for people with learning disabilities. He suggests that, for this client group, interventions that are called 'therapy' can, by definition, set apart learning-disabled people from the rest of society. He argues that music therapy has the potential to help any person, regardless of disability, to relate positively to others, therefore bringing the learning-disabled population on to the universal spectrum of relating to others. This, Gale suggests, contributes to what he describes as the 'normalisation' of people with learning disabilities.

In the 1980s and 1990s some music therapists were working to relieve physical symptoms through the use of music therapy. Oldfield (1985) documented separate, collaborative work, with both a physiotherapist and a speech and language therapist, to bring about an improvement in physical symptoms. Later, Hooper and Lindsay (1990) studied the effects of music therapy on anxiety and Skille, Wigram and Weekes (1989) and Hooper (2001) have both also studied the effects of vibroacoustic therapy.

Although the 1990s was a fruitful time in terms of the publication of general music therapy research, as Watson (2007) observed, clinical work with adults with learning disabilities was published less frequently than clinical work in other fields.

Among the work that was published, Ritchie (1993) documented music therapy with clients with learning disabilities and challenging behaviour and both Bunt (1994) and Ansdell (1995) made brief references to work with learning-disabled clients. In the same year, Heal-Hughes (1995) made a comparison between mother-infant interactions and how these might be replicated in the client-therapist relationship. In 1998, Agrotou completed her PhD which investigated adults with learning disabilities and their carers. Her research explored group music therapy for profoundly learning-disabled adults and also involved carers participating in the music therapy group. Alongside their participation in the music therapy groups, the staff also took part in what Agrotou described as *free discussion group meetings.* She describes the ways in which she and the carers, in a spirit of 'shared self-questioning, of trust about admitting and sharing our doubts and difficulties' (Agrotou, 1998, p. 86) could mutually examine their thoughts and feelings towards the patients and the music therapy group process. Agrotou facilitated these groups and describes their function in the following way:

> 'Our free-discussion group meetings intended to bring about changes of attitude, without being teaching sessions; they included certain elements of psychotherapy without being psychotherapeutic; they aimed at the acquisition of music therapy skills although they were not geared towards music therapy training.'
>
> (Agrotou, 1998, p. 82)

Findings from the study show that the patients moved from being very isolated to becoming more creative and autonomous as well as seeking greater human intimacy. The carers in the study changed from initially being emotionally unresponsive to their patients, to gradually becoming much more interested in them and taking on a role that approximated to a music therapy assistant within the groups. This study has some obvious resonances to my own research with its interest in the experiences of the carers. By attending to the experiences of the carers in her study, Agrotou has shown that this can have a positive outcome in terms of how carers engage with their patients.

During the following year, Ford (1999) studied the effects of music on the self-injurious behaviour of a woman with severe developmental disabilities. Lawes and Woodcock (1995) also described their research using music therapy with learning-disabled adults who self-injured and Lundqvist, Andersson and Viding (2009) investigated the impact

of vibroacoustic therapy on aspects of challenging behaviour, including self-injury in individuals with autism and developmental disabilities. These three studies study the effects of music therapy upon self-harm and will be considered more fully in §2.3.10. Writing in the UK in 1994, Toolan and Coleman published a paper in the Journal of Intellectual Disability Research describing the processes of engagement and avoidance in five people with learning disabilities. In the same journal, Lindsay et al. (1997) compared the effects of four therapy procedures on concentration and responsiveness in people with profound learning disabilities. Common to each of these case studies is the format of showing developments in music therapy over a period of time.

2.3.7 Music therapy and group work: 2000s

The 2000s have seen increased debate and interest in the field of learning disabilities, with greater emphasis given to group work and the place of music therapy within a more multidisciplinary context. Hooper et al. (2004) wrote about sensory integration, paying particular attention to how music therapy takes its place alongside the MDT. In 2002, Richards and Hind (now Ogilvie) wrote about how the concept of secondary handicap and the work of Foulkes and Winnicott shaped their thinking in a music therapy group for adults with learning disabilities (Richards and Hind, 2002). In 2005, Warner wrote about group music therapy with adults with learning difficulties and severely challenging behaviour in fulfilment of her PhD. Warner's research had two components to it: the music therapy groups which took place in a community residential home, and a context where home staff, music therapists and daycare workers could reflect on what Warner describes as *'the impact, benefits, barriers and threats to the music therapy process'.* (Warner's research will be discussed further in relation to the present thesis in §8.3.5.) More recently, Bevins et al, (2015) also described some work which takes into account the views of a staff team about a music therapy group for adults with intellectual disabilities and dementia. Further group work was described by Watson and Vickers (2002), who ran an art and music therapy group, offering 12 weeks of each discipline, focusing on themes arising from the initial referrals of people to the group. In 2006, Leaning and Watson described a new project that aimed to develop communication, interaction and emotional literacy skills in people with profound and

multiple learning disabilities. Later, Cho (2013) described a group for adults with learning disabilities that explored anti-group phenomena, described by Nitsun (1996). Cho illustrated this concept through case work discussion of a slow open group. In the following year, research carried out by Pavlicevic et al. (2014) studied the use of improvisational music-centred music therapy for young adults with severe learning disabilities to promote confidence, self-esteem and friendship.

2.3.8 Music therapy and autism

A number of music therapists have written specifically about work with people with autism. Atkinson (2003) wrote a case study about her work with a man with autism. Endings were a dominant theme in this work which also centred on providing a safe environment in which her client could move from a place of chaos into a place where he was able to reflect on his feelings. Hillier, Greher and Poto (2011) demonstrated positive outcomes in a research study investigating participation in a music intervention for young adults on the autistic spectrum. The authors measured the effects of music interventions on anxiety, self-esteem, and relationships with peers; a significant reduction in anxiety was observed. In Italy, Boso et al. (2007) described the effects of long-term interactional music therapy on the behaviour profile and musical skills of young adults with severe autism, whilst Kargiou (2012) used music to address self-injurious behaviour in people with autism in Greece. A thorough search of Kargiou's research revealed the main body of the text to exist only in Greek. A translation via Google translate was made for the purposes of understanding as much as possible about this research. Kargiou investigated the effects of music on the self-injurious behaviour of ten children with autism. She was interested in whether engaging in music therapy brought about a reduction in self-harming during the sessions and whether a specific technique or musical instrument was especially effective. The research showed that there was no particular technique or instrument that was responsible for reducing self-injury, although the research found that engaging in music therapy for the duration of the session reduced self-injurious behaviour for that period of time. The participants found that music therapy helped them to feel relaxed and the author concluded that, within the context of a therapeutic relationship, music therapy can help to reduce self-

injurious behaviour. In the Netherlands, Dimitriadis and Smeijsters (2011) acknowledged that people with autism may often demonstrate a particular interest in certain musical components such as rhythm, pitch, timbre or harmony, and offered explanations on why music can be of particular benefit to this client group. Bergmann et al. (2016) described their work in Germany where their use of music contributed to a diagnosis of autism in adults with learning disabilities.

2.3.9 Music therapy and adults with learning disabilities: 2000–2017

There have been two significant overviews of music therapy with learning-disabled adults since 2000: in 2007, the American music therapist Laurie A. Farnan gave an overview of music therapy with people with developmental disabilities. A year later, a collaboration between Hooper, Wigram, Carson and Lindsey (2008) reviewed the music and intellectual disability literature with a particular emphasis on examining surveys that considered client responses, issues of methodology, reports about clinical settings, music therapy provision, the benefits of improvisation and receptive music therapy techniques. Odell-Miller, responding to a lack of any guidelines for the referral process and assessment of adults with learning disabilities in music therapy, explained how she devised a research project with Darnley-Smith in 2001, surveying staff views about the efficacy of music therapy for this clinical group. Similarly, in Australia, Churchill and McFerran (2014), also responding to a lack of guidelines within which to assess people with profound learning disabilities, were working to develop a music therapy assessment tool that was specific to people with severe multiple disabilities. Both of these pieces of work, Odell-Miller and Darnley-Smith, 2001 and Churchill and McFerran 2014, promoted the value and effectiveness of music therapy for adults with learning disabilities.

In the UK in 2010, Ruck published her work about endings in music therapy work with learning-disabled adults. Her work used SSIs and a questionnaire to explore the efficacy of endings in music therapy with adults with learning disabilities. Ruck concluded that there is a difference between the endings that most therapists hope to achieve and what might be realistically possible within the context of different work settings. Among her

conclusions, she acknowledges the importance of developing good relationships with parents and carers, given the role that they will continue to have in the client's life once music therapy has finished. In the same year, Margetts (2010) documented her work using fairy tales in music therapy. Her case-study describes an older man with learning disabilities who was placed into an institution early in his life. Following five years of music therapy, he expressed curiosity about a well-known fairy-tale. Margetts describes how the story was incorporated into the work and was used to address issues of institutionalisation and social change. She considers the ways in which fairy tales explore the different trials of their characters and describes the ways in which this has significance for people with learning disabilities and may resonate with aspects of their own experience. In Australia, music therapists have been regularly publishing work about learning-disabled adults: in 2013, McFerran and Shoemark demonstrated how musical engagement promoted well-being in education for a young man with profound and multiple disabilities: they based their research around a central tenet that young people with intellectual disabilities disorders (IDDs) have the right to participate in educational opportunities and to have meaningful relationships. The authors acknowledge that having positive relationships is linked to student well-being. Video analysis was used to examine in depth, the relationship between a young man with IDDs and his music therapist. Conclusions from this study showed that the essence of the communication between them involved the combination of the music therapist being attentive and responsive and also acknowledged the benefits of creatively being with another person over time. Lee (2014) conducted a phenomenological study of interpersonal relationships between five music therapists and adults with profound intellectual and multiple disabilities. In common with McFerran and Shoemark, Lee also wanted to understand something of the quality of the relationship between a music therapist and a client with significant learning disabilities. In her study, Lee sought to investigate the experience of the interpersonal relationships between 5 music therapist and their clients with PIMD (profound intellectual and multiple disabilities). Lee recruited five pairs to her study, a pair consisting of a person with PIMD and their music therapist. She conducted interviews which sought to elicit information about what the therapists considered to be meaningful moments within a music therapy session with their client. A significant conclusion from Lee's study is that four out of five

participants felt that music therapists had a unique role in meeting the psychological needs of their clients. The exploration of communication and musical engagement between music therapists and adults with profound disabilities in Australia continued in 2015 with the publication of four case studies by Thompson and McFerran (2015). These case studies examined communication and engagement through musical interactions for young people with profound intellectual disabilities and developmental disabilities. Examining the impact of music therapy upon the communicative behaviour of young people with profound intellectual disabilities disorders, Thompson and McFerran video-recorded and analysed individual music therapy sessions and toy play sessions with the same therapist. Comparing these two interventions, the authors concluded that slightly more communicative behaviours were evident in the music therapy sessions, particularly in response to singing. They suggest that music therapy creates conditions that facilitate engaging and motivating interactions.

In the US, Hoyle and McKinney (2015) described using music therapy to address bereavement for adults with learning disabilities. The study explored the use of music therapy with three adults with learning disabilities who had experienced a bereavement of a family member. Group sessions over nine weeks offered an educative element about death as well as the opportunity to reflect upon the feelings that might emerge following bereavement. The authors concluded that the client for whom there was the most positive change had lived within a family home for the longest, before moving to residential care. They suggest that living with family into adulthood may correspond to the formation of deeper attachments and therefore a greater bereavement response. The two participants who showed no change in terms of negative behaviours had both lived in a residential facility for over forty years. The authors speculate about whether living away from the family home for such a long time had an impact upon the significance of their relationships with their family members and therefore upon their grief reactions.

Music therapists in practice today are aware of the need to find effective ways to evaluate their work. Service providers are also increasingly expected to show positive progress and predictable outcomes for the people they support. In seeking to address some of these issues, Roman (2016), in her paper entitled *Were they better today?,*

wrote about ways to evaluate her clients' therapeutic progress within the context of the institution's expectations of positive change and predictable, measurable outcomes. Roman explores both internal and external pressures within and outside of the music therapy encounter. She describes the external pressures in terms of a growing pressure to prove the value of music therapy. The internal pressures are described as the therapist's desire to understand the client. The particular anxieties that these pressures create are explored through a case study. In conclusion Roman considers the impact of social and political issues upon the therapeutic encounter and the need to provide evidence of the efficacy of music therapy at a time when funding cuts to therapy provision are significant.

2.3.10 Research in music therapy and self-harm

The prevalence of self-harm within the learning-disabled community will be discussed in more detail in §2.6, but given its significance, there is very little research that considers its place within the music therapy encounter. Whilst there are book chapters and papers about music therapy with people with learning disabilities, for whom self-harm might be a part of their presentation (Richards; Saville; Warner; Watson, all writing in Watson ed., 2007), there is very little literature that focuses specifically on self-harm and music therapy. There is, however, significant literature on these areas within the wider arts therapies professions: examples of these include self-harm and art therapy (Milia, 2000) and self-harm and dramatherapy (Dokter and Holloway, 2011).

The two studies that most directly consider the impact of music therapy upon adults with learning disabilities that self-harm are those by Lawes and Woodcock (1995) and Ford (1999). In 1995, Lawes and Woodcock investigated the use of music therapy with four adults with severe learning disabilities who engaged in self-injurious behaviour (SIB). Service-users were offered fifteen sessions of therapist interaction, followed by twenty-eight sessions of music therapy. The authors described the results as showing no reduction in SIB, nor an increase in communication skills. However, they observed that the variations in SIB were 'significantly associated with the functions that it served for each person' (Lawes and Woodcock 1995). This potentially invites questions about

whether self-harm could be considered within a broader spectrum of communication, which the authors indeed reflected upon. Certainly other writers investigating self-harm outside of a music therapy context, have also considered self-harm from the perspective of a communication of emotional distress or trauma (Dick et al., 2010; Hill and Dagnan, 2002; Dickinson and Hurley, 2011). My own research aligns itself closely to this paradigm, seeking, as it did, to understand the meaning that self-harming had for the two participants in the study.

The second research study took place in America in 1999. Ford compared the effects of contingent blocking, receptive and active music-making with a non-musical activity (water play) on three aspects of self-injury in a young woman with severe learning disabilities. The aspects of self-injury were: bruxism (teeth grinding), mouth-scratching and head-hitting. The young woman was videotaped for ten minutes before and ten minutes after each of the four interventions. Contingent blocking was a way of minimising significant injury to the young woman's head by the therapist placing her hands on the client's head to intercept and prevent further head-hitting. Receptive music-making involved ear phones being placed around the woman's head whilst music was played to her. During active music-making the client was offered an electronic keyboard which was placed in front of her; the music therapist responded to any sounds that she made. The non-musical activity was water play: a small tub of warm water was available with sponges and balls. The client was encouraged to explore the water alongside the music therapist who gently squeezed water from a sponge over her hands. The results from this study showed that the overall SIB remained the same although there was some reduction in teeth-grinding after listening to music through ear phones, and head-hitting was reduced by contingent blocking and following water play.

Certain similarities exist between these two studies: each used video analysis to observe SIB following specific interventions; in both studies, the subjects had severe learning disabilities and were unable to use language; both studies alluded to the impact of such SIB on both the subjects as well as the staff that cared for them, although neither study addressed the challenges faced by staff. In conclusion, both studies found no significant reduction in SIB as a result of music therapy, although both studies recommended

further research in this area and suggested specific ways in which future research in this field might be developed.

In 2009, the effects of vibroacoustic therapy on challenging behaviours including SIB was investigated by Lundqvist, Andersson and Viding. Twenty learning-disabled adults, half of whom had an additional diagnosis of autistic spectrum disorder (ASD) as well as developmental disabilities, were offered vibroacoustic treatment. This involved the participants sitting in a vibroacoustic chair which had built-in speakers through which vibrations between the frequencies of 30–80 Hz were generated. Further loudspeakers produced auditory sounds and during the treatment a song was played through the speakers. The song, volume of the music and intensity of the vibrations remained unchanged throughout the study. Sessions lasted for twenty minutes and were videotaped for analysis. The results suggested that incidences of SIB and other challenging behaviours, including stereotypical behaviours and aggressive destructive behaviour, decreased as a result of receiving vibroacoustic therapy.

In this next section of the literature review, self-harm will be considered: how it is defined, how it can be socially acceptable within a particular context, its statistical implications and what it means for the purpose of this research study.

2.4 Self-harm

Self-harm can take a number of different forms, sharing in common the inflicting of non-life-threatening harm to the body. The idea of intention is significant; if the intention is to threaten life, the action then becomes framed within a suicidal context. Methods of self-harm commonly include cutting or burning the skin, ingesting foreign objects, self-poisoning, hitting or banging parts of the body, breaking bones, scratching and interfering with the natural wound-healing process.

2.4.1 Towards a definition of self-harm

There are a number of different definitions of the term 'self-harm'. The National Institute of Health and Care Excellence (NICE) guidelines in 2013 offer the following definition:

'self-poisoning or self-injury carried out by a person, irrespective of their motivation.'
(NICE, 2013, p. 6)

This differs from the term 'attempted suicide' because it suggests that the purpose of the act of self-harm may not be the intention to die. It allows for the idea that there may be a number of motivations, both conscious and unconscious, behind an act of self-harm.

Interestingly, the service-users' National Self-Harm Network (NSHN) gives a description of self-harm which invites the possibility that self-harm might be a necessary means of survival and, perhaps paradoxically, a way of preventing suicide:

'Self-injury is frequently the least possible amount of damage and represents extreme self-restraint.'
(NSHN, 1998)

Matthew Nock defines it as:

'direct and deliberate destruction of body tissue in the absence of an observable intent to die.'
(Nock, 2010, p. 342)

2.4.2 Self-harm as a form of hope

The idea suggested by the National Self-Harm Network's definition that self-injury represents extreme self-restraint is a view that resonates with some contemporary psychotherapists writing about self-harm today. Motz, editor of a collection of papers under the title *Managing Self-Harm: psychological perspectives*, suggests that 'self-harm is fundamentally an attempt to stay alive' (Motz ed., 2009, p. 6). Motz refers to Winnicott's (1956) idea that antisocial tendencies are a sign of hope:

'…the act of aggression, apparently destructive and hopeless, in fact reflects the antisocial person's hopefulness in an environment that can recognise and meet their needs.'

(Motz ed., 2009, p. 6)

Gardner, in her book, *Self-harm: a psychotherapeutic approach*, begins by quoting from a poem written by a young patient in which she describes self-harming as a means of confirming that she was real, alive and in control. Gardner describes coming to understand her patients' attacks on their bodies as 'metaphoric representations for earlier psychic wounds' (Gardner, 2001, p. 4).

Turp (2003) discusses the area of culturally accepted self-harming acts ('cashas') and the overlap between this and what she describes as the 'florid and dramatic examples' (Turp, 2003, p. 9) of self-harm that are more frequently referred to. She is interested in these more hidden narratives of self-harm and how these can be understood within the therapeutic encounter.

2.4.3 Socially acceptable self-harm

Within its broadest context, self-harm, or the capacity for causing self-inflicted damage to the body, can take many socially acceptable forms. Excessive alcohol consumption, over- or under-eating, the use of recreational drugs, piercing or tattooing the skin and taking excessive exercise could be considered as examples of how harm is knowingly inflicted upon the body in ways that society deems as both acceptable and at times even desirable. Certain tribal rituals often have initiation ceremonies which inflict considerable physical pain, the forbearance of which denotes a successful rite of passage from childhood to adulthood. Such ceremonies may involve marking, branding and causing permanent physical changes to the body (Peoples and Bailey, 2014). Although this differs in obvious ways from inflicting pain to the self, these initiation rites and ceremonies carried out by others are perhaps worthy of mention because the person being initiated is knowingly allowing themselves to be harmed.

2.4.4 Statistical implications of self-harm

It is widely acknowledged that self-harm is an extremely complex and challenging behaviour that has wide-reaching implications for both staff teams and the emergency medical staff who may need to attend to self-inflicted wounds (Skegg, 2005; Nock, 2010; Birch et al., 2011). It is also costly to the UK's National Health Service (Larkin, Di Blasi and Arensman, 2014). Studies conducted over the last 15 years suggest that rates are steadily increasing (Owens, Horrocks and House, 2002; Klonsky et al., 2003; Cook et al., 2004, Nock, 2010; Brown and Kimball, 2013; Ougrin and Boege, 2013). In 2016, the Mental Health Foundation published findings from the 2014 Adult Psychiatric Morbidity Survey which shows recent statistics relating to mental health across a broad demographic. The survey acknowledges the difficulties in gathering reliable statistics about self-harm and bases its figures on the number of hospital admissions due to self-harming. The findings show a steady increase, over a decade, of admissions due to self-harm: 91,341 admissions between September 2005 and August 2006 increasing to 112,096 between September 2014 and August 2015. The survey also shows that in 2014, 7.3% of people stated that they had self-harmed at some point in their life: the rate was higher in women, 8.9%, with men having a lower prevalence rate of 5.7%. Other studies show that those who are particularly vulnerable to self-harm include people with borderline personality disorder, which includes people described as having an emotionally unstable personality disorder (Black and Grant 2014) and those who live within difficult socio-economic circumstances (Klonsky et al., 2003; Chapman et al., 2005; Haw and Hawton, 2008; Turner et al., 2015). Haw and Hawton, writing in 2008, looked at the correlation between acts of deliberate self-harm (DSH) and pre-disposing risk factors across the life cycle. They found that, whilst psychiatric disorders are common in patients who self-harm, there are a number of other factors that both pre-dispose somebody towards self-harm and also act as protective factors against it. Pre-disposing factors include unemployment, financial hardship, relationship difficulties and illness. The authors also found that for a woman, having a child may act as a protective factor against self-harm. The study revealed that patients admitted to hospital following an episode of deliberate self-harm had experienced a significant increase in difficult life events in the three weeks leading up to the admission. For men, the

problems were due to difficulties with housing, finances, employment and drug and alcohol abuse, whereas for women the problems were with relationships, eating disorders, childhood abuse and psychiatric disorders. Whilst suicide rates were higher within young men, rates of self-harm were found to be greater among women. These findings are substantiated by other studies (Skegg, 2005; Birch et al., 2011), although further studies (Stanley et al., 2001; Briere and Gil, 1998) suggest that there are no significant gender differences and that there is an equal distribution of self-harm amongst both men and women. It is difficult to understand the reasons for such discrepancies between studies; it is perhaps significant that more recent studies indicate a greater prevalence amongst women whereas older studies see a more even distribution between genders. As I have been conducting this literature search I have come across more books and studies that focus exclusively on women (Smith, Cox and Saradjian, 2002; James and Warner, 2005; Gratz, Tull and Levy, 2014). It is not clear why this emphasis exists but it is perhaps significant that within the media there seems to be a current trend of reporting about self-harm within predominantly female groups: women prisoners, post-partum psychosis in new mothers and young adolescent girls being particular recent examples in the British news.

2.4.5 Self-harm and mental health

The Mental Health Foundation report, discussed in §2.4.4, states that whilst self-harm is not considered a mental illness in its own right it often occurs as a result of mental distress. It is my experience that people with mild learning disabilities often have a higher prevalence of co-morbidity (often a psychiatric disorder) described as a dual diagnosis: a learning disability with a mental illness. Cooper et al. (2007) estimate that over 40% of people with a learning disability have a co-existing mental health problem.

This section of the literature review has discussed possible definitions of self-harm, how it is considered with a socially acceptable context, the statistical implications of self-harm and how it links to mental illness.

The next part of this review will consider the term 'learning disability' and what is meant by this.

2.5 What is a learning disability?

There are several organisations in the UK dedicated to supporting people with learning disabilities. One of these, Mencap, offers the following definition of learning disability:

'A learning disability is a reduced intellectual ability and difficulty with everyday activities for example household tasks, socialising or managing money which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people.'

(Mencap, n.d.)

It is important to distinguish this from a learning *difficulty* which may suggest a particular problem with a specific aspect of learning, e.g. dyslexia. A learning *difficulty* is different from having a global disability which affects all aspects of a person's intellectual ability in an ongoing way. It is also different from mental illness which describes a psychiatric disorder from which recovery is potentially possible. A learning disability is a lifelong condition.

In 2001 the UK produced a White Paper entitled *Valuing People: a new strategy for learning disability for the 21st century*. It offers the following definition of learning disability:

- 'a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.'

(Department of Health, 2001, p. 14)

Learning disabilities are often categorised as profound, severe, moderate and mild and these categories refer to the severity of the impairment and the amount of support required for the person to achieve as much independence as possible.

2.5.1 Categories of learning disabilities

IQ (intelligence quotient) is a score that measures human intelligence through a number of standardised tests. One of the most widely used of these, the *Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV)*, published in 2008 by the Psychological Corporation, uses ten core subtests and five supplementary subtests. These subtests measure four categories of intelligence: Verbal Comprehension Index (VCI); Perceptual Reasoning Index (PRI); Working Memory Index (WMI) and Processing Speed Index (PSI). Together the scores of these four categories combine to give a Full Scale IQ. The current WAIS-IV classifies IQ in the ways listed in Table 2.1.

IQ Range ('deviation IQ')	Classification of Intelligence
130 and above	Very Superior
120–129	Superior
110–119	Highly Average
90–109	Average
80–89	Low Average
70–79	Borderline
69 and below	Extremely Low

Tab. 2.1: Current Wechsler (WAIS–IV) IQ classification (Wechsler, 2008)

People with a mild learning disability have an IQ in the range of 50–70. The two service-user participants in this study fell within this category in the IQ range. Those with a mild learning disability usually have enough language available to them to hold a conversation and are able to communicate their ideas and needs effectively. They may be able to attend to most of their care needs and accomplish everyday living tasks. People with mild learning disabilities are sometimes undiagnosed and unknown to local services, often because they are living successfully in the community with ageing parents or relatives. When these carers are taken ill or die, a neighbour or family member may then refer to local services and in middle age somebody may receive a

diagnosis of a mild learning disability and come under the care of local services for the first time. People with a moderate learning disability fall into the IQ range of 35–50. It is likely that they will have sufficient language available to them to communicate their needs. People with a severe learning disability have an IQ between 20 and 35. Whilst their needs may still be complex, people with a severe learning disability may be able to communicate with basic words to make their needs known. People with profound learning disabilities have an IQ of less than 20 and are likely to have multiple and complex needs. It is often the case that they may have extensive physical needs and require support with mobility. People with profound learning disabilities usually have significant communication difficulties and may be non-verbal.

People with learning disabilities find it difficult to learn and retain new information. They may encounter difficulties with communication, and in addition may have a number of physical problems, requiring daily support. Somebody with a learning disability may find it difficult to analyse risk which may leave them potentially vulnerable to abuse and exploitation.

2.5.2 The term 'learning disability' and its history

Valerie Sinason, in her 1992 seminal book '*Mental Handicap and the Human Condition*', outlines the number of changes of labels that the learning-disabled population has had to endure:

> "The existence of disability, handicap, and handicapping processes is so painful that each culture and historical period has tried to evade the issue by a frequent change of terms. No other subject has been prey to this amount of change. Within my own working life there have been the terms 'retardation', 'subnormality', 'handicap', 'special needs', 'learning difficulty' and 'disability'."
>
> (Sinason, 1992, p. 2)

The earliest reference to what we today refer to as a learning disability is found in the Lunacy Act of 1845. No distinction was made here between learning disability and mental illness, with the Act defining a lunatic as an 'insane person' whose capacity for lucidity of thought may be prone to fluctuation. Blackstone, writing in 1765, describes:

> ‘a lunatic, or non compos mentis, is one who has had understanding, but by disease, grief, or other accident has lost the use of his reason. A lunatic is indeed properly one that has lucid intervals; sometimes enjoying his senses, and sometimes not, and that frequently depending upon the change of the moon.’
>
> (Blackstone, 2016, p. 196)

In 1886 the Idiots Act attempted to make a distinction between those with a mental illness (‘lunatics’) and those with a learning disability (‘idiots and imbeciles’). A decade later, in 1896, a pressure group entitled the National Association for the Care and Control of the Feeble Minded was established in Britain; its purpose was to facilitate the segregation of disabled people from the rest of society. Against a social background in Britain and the US that promoted the selective breeding of human individuals, Francis Galton, a cousin of Charles Darwin, established the eugenics movement. Dedicated to developing ‘strong and hearty individuals’ (Galton, 1869, p. 410), Galton advocated that the reproduction of those considered to be feeble-minded should be stopped. In 1907 Galton founded the Eugenics Education Society, which campaigned for both sterilisation and marriage restrictions for those the Society considered weak. The purpose of this was for ‘the undesirables [to] be got rid of and the desirables multiplied’ (Pearson, 2011, p. 348). The following year, the leading British psychiatrist, neurologist and collaborator of Charles Darwin, Sir James Crichton-Brown, was addressing the Royal Commission on the Care and Control of the Feeble-Minded in 1908. He recommended compulsory sterilisation for all women with learning disabilities and those suffering from mental illness. It is perhaps rather controversial to note that, over one hundred years later, in February 2015, a judge in Britain authorised the compulsory sterilisation of a woman with learning disabilities. The arguments were doubtless complicated and rested on considerations that included the risk to the mother’s health if a further pregnancy occurred and whether or not she had the mental capacity to understand and act upon the advice she was offered. Answers to such complex situations raise considerable ethical and moral dilemmas but in more recent times people are thought about according to their situation and broader needs, rather than simply being sterilised because they have a learning disability.

The next Act to be passed was the Mental Deficiency Act which came into existence in 1913; the Act was amended in 1927 to take into account a disability acquired through accident or illness rather than just being present from birth. An acquired disability was

suggested by the terms ‘moral-imbecile’ and ‘moral idiot’. The term ‘moral defective’ remained a prevalent term until the implementation of the Mental Health Act of 1959. People considered to be ‘moral defectives’ at this time were usually those who showed criminal tendencies and those for whom attempts at behavioural modification had little or no effect; unmarried mothers were included in this category.

Between the 1920s and 1940s the first institutions, or ‘colony buildings’ as they were known, started to be built. The colony at South Ockendon admitted its first so-called ‘mental defectives’ in 1931. A ‘colony’ was a self-contained community, sometimes referred to as a ‘village’ and populated by people with a learning disability who lived separately in same-sex ‘bungalows’ or ‘units’ built around the colony. Often these ‘colonies’ or ‘villages’ were situated in rather remote, rural locations. Although people might have had certain freedoms to walk around the grounds of the colony, people with learning disabilities were segregated by gender, thus reducing further any opportunities for contact with the opposite sex. This lessened the likelihood of pregnancy and reproduction.

In 1944, four years before the National Health Service was established, the Education Act and the Disabled Person’s Employment Act came into being. Somewhat ironically, given the implementation of the Education Act, terminology was changed at the same time to refer to people with learning disabilities as ‘ineducable’. The next significant piece of legislation was the introduction of the Mental Health Act in 1959. This Act was designed to repeal the Mental Deficiency Act of 1913 (amended in 1927). It encouraged a model of community care, whilst acknowledging that few resources were available to develop this vision. It was advised by government officials of the time that people should not be admitted to hospital unless they were at significant risk or posed a danger to themselves or others (what we now refer to as being ‘sectioned’). The term ‘sectioned’ refers to a voluntary or involuntary admission to hospital under the Mental Health Act. This means that somebody can be admitted to hospital with or without their agreement, with the Mental Health Act being invoked as the authority for such a detention. The decision to detain somebody under the Mental Health Act is made by two doctors (one of whom must be a psychiatrist or somebody otherwise trained in the

assessment of mental health) and an Approved Mental Health Professional (AMHP). The AMPH may be a social worker, nurse, psychologist or therapist. The term 'section' refers to the section or paragraph of the Mental Health Act under which a patient is detained and the different sections refer to different treatment options. Detention under a 'section 2' for example, means that the patient is detained for 28 days during which time their mental health is assessed. A 'section 3' involves a treatment plan lasting up to 6 months which can then be renewed for a further 6 months or annually. People can be sectioned if it is thought they may have a mental illness requiring treatment and that they may pose a risk to themselves or others.

In 1961, Enoch Powell, the Minister of Health, announced that the closure of long-stay institutions would start happening in 15 years; in fact the first hospital, Starcross in Exeter, closed 25 years later in 1986. By 1964 the Tizard Community Services for the Mentally Handicapped were advocating small residential units as an alternative to people living in long-stay institutions and, by 1971, a Department of Health White Paper, *Better Services for the Mentally Handicapped*, recommended the Care in the Community model.

2.5.3 Care in the Community

Although the government White Paper, *Better Services for the Mentally Handicapped,* recommended the Care in the Community model, as we know from §2.5.2, it was to be a further 15 years before long-stay institutions started to be closed, and people were resettled into new homes in the community. Sir Roy Griffiths, NHS advisor to the government, produced a report (Griffiths, 1988) entitled '*Community Care: Agenda for Action*'. Known as the Griffiths Report, it outlined six key areas concerned with commissioning, funding and the roles of social services and local authorities. The Department of Health responded to this in 1989 with its White Paper '*Caring for People: Community Care in the Next Decade and Beyond*'. The White Paper made proposals for new funding structures, a greater promotion of the independent sector, the development of needs assessment and care management, provision of day care and also

respite care and practical provision for carers. The Community Care reforms came into place in April 1993.

2.5.4 Mary Warnock and the Warnock Report (1978)

The 1970s and 1980s saw some considerable changes in educational policy. The ways in which people with learning disabilities were thought about with regard to education and housing were given more careful attention. The 1944 Education Act described eleven categories of disability, including those that were 'blind', 'educationally subnormal' and 'delicate', with some children considered to be 'uneducable'. Regardless of the nature of a child's disability, the culture was for them to attend a local school with no acknowledgement or provision made for any educational difficulties they might have experienced. With a lack of any specific help and little expectation of the potential for development or growth, many children were expelled from school and taken into a learning disability institution where further educative opportunities were mostly unavailable or, at best, extremely limited. The establishment of the Warnock Committee in 1974 yielded the Warnock Report (Warnock, 1978), marking a radical shift in thinking within the field of special education. The chairwoman of this committee and subsequent report, Helen Mary Warnock, Baroness Warnock, is an English philosopher who has written extensively on ethics, education and philosophy of mind. Born into a large family in 1924, Warnock was brought up by her mother and a nanny following the death of her father. She had an older brother who had autism although Warnock never knew him as he was cared for in a nursing home. Whilst pursuing a teaching career in the 1960s, Warnock was appointed to a seat on the Oxfordshire local education authority. Her background in education led to her being invited to Chair an inquiry on Special Education in 1974. The report arising from this inquiry was published in 1978 and marked a significant change in how children with learning disabilities were able to access education. The report recommended that children came under the care of the Local Education Authority instead of the Health Service and were therefore entitled to an assessment of their needs. This marked the implementation of what we now know as a statement of educational needs where each child is assessed and given appropriate support to engage with the opportunities that

school life and education offers. The recommendations of the Warnock Report were authorised in the 1981 Education Act. Although Warnock later considerably revised some of her views from the 1978 report, even calling more recently for a new inquiry, the legacy from the original report has, nevertheless, been long-lasting and is considered ground-breaking. In particular, the inquiry brought about the introduction of statementing for children with special educational needs. A statement of special educational needs is a formal document outlining a child's particular difficulties in relation to learning. It also details the type of provision the school will provide to address such difficulties. The process begins with a statutory assessment, carried out by the local education authority and often in conjunction with other agencies such as Social Services, an educational psychologist, GP, the child's parents and the school. The assessment will investigate all aspects of the child's learning needs and abilities. Once a statement has been issued, parents have the right to decide at which school they would like their child to be educated. Although this outcome from the Warnock Report is still in place within education today, Mary Warnock, in a follow-up report in 2005, acknowledges that some aspects of the inquiry have led to confusion. She articulates the dilemma between emphasising the 'sameness' of all children, in other words, promoting equality and inclusiveness, whilst also being able to healthily acknowledge difference in a way that is not only to do with giving a child a potentially pejorative-sounding label. In their book, '*Special Educational Needs: A New Look'*, Warnock and Norwich (2010) say of statementing that:

> 'while being a valuable attempt to avoid "categorising" children into fixed disabilities and hence to avoid "labelling" them, the introduction of the concept of special educational needs has however led to a problematic tendency to refer to children with very different needs as if they were all the "same", i.e. special educational needs (SEN) children.'
>
> (Warnock and Norwich, 2010, p. 4)

There exists a continuing difficulty in using a generic term such as 'learning disability', which, at worst, might keep the person it describes in a very fixed, handicapped place in the minds of others, whilst simultaneously finding ways to acknowledge the same person's individuality, strengths, creativity and resourcefulness.

As the 1980s continued there was the first successful campaign by three people with learning disabilities to vote in General Elections. By the end of the 1980s the first long-stay institutions were starting to close and community group homes were starting to be established. The building of community group homes gathered pace in the late 1980s and 1990s and long-stay institutions closed as people gradually started moving into homes in the community. In 1989 another White Paper, '*Caring for People*', was published with a strong emphasis on living in the community.

In the 1990s the Community Care Act and the Disability Discrimination Acts were passed and the Department of Health used the official term 'people with a learning disability.' The 2000s have seen some significant developments but have also revealed some concerning examples of endemic abuse within community learning disability provisions. Important legislation includes the 2001 White Paper '*Valuing People*', which sets out the rights for learning-disabled people to have choice, independence and to take an active and inclusive role within society. 2007 was a particularly significant year which saw the UN Convention on Human Rights of Persons with Disabilities. The UK added its signature to this important legislation; countries signing up to this demonstrated a commitment to uphold the rights of disabled people. Mencap published two significant reports, one in 2007 and another in 2012. Both are concerned with inequalities in NHS care which have led to the deaths of people with learning disabilities, '*Death by Indifference*' in 2007, and '*Death by Indifference: 74 deaths and counting*' in 2012. There has been no new legislation in respect of people with learning disabilities since 2012.

In Table 2.2 I summarise some of the key changes in the terminology from 1845 to the present. As this timeline suggests, for a long time people with learning disabilities were considered incapable of learning. Until the late 1950s the terms used to describe people with learning disabilities were extremely pejorative by today's standards, possibly reflecting society's fear and lack of understanding at the time. The original intention behind some of these terms that we now consider pejorative was to find a neutral term not intended to be punitive or diminishing to a person with learning disabilities; it seems that as the terms came in to common parlance they gradually became terms of abuse.

1845	lunatic – no distinction made between people with learning disabilities and those with mental illness.
1846	simpleton, later replaced by moron
1886	idiots/imbeciles
1895	retarded – not pejorative at the time but by the 1960s had become a term of insult
1908	mental defective
1913	idiot/imbecile/feeble-minded
1927	moral defective/moral imbecile
1931	mental defective
1944	ineducable (mental defective still in usage)
1950s	severely subnormal/backwards
1964	mental handicap
1980s	person with a mental handicap
1990s	person with a learning disability

Tab. 2.2: Key changes in terminology

2.5.5 The possible impact of having a learning disability

It is possible that for some parents, the birth of a baby with learning disabilities may represent a trauma; some parents may experience profound grief for the loss of the idealised baby, the child that has not come to be (Sinason, 1992; Waitman and Conboy-Hill eds., 1992; Hollins and Sinason, 2000). For other families, a diagnosis of a learning disability may come much later, with any difficulties not known at birth and only becoming obvious as the child becomes older and ordinary milestones are perhaps not met. In both cases, a combination of parental grief and the child's difficulties may mean that a secure attachment is sometimes difficult to establish. It is common for all expectant parents to wonder and imagine about their unborn child and to hold many hopes and expectations both conscious and unconscious about the child that will come to be. However loved and accepted a baby with learning disabilities might be, as Ditchfeld (1992) suggests, few people would actively hope to give birth to a disabled child. Although parents constantly modify their expectations and aspirations for their children it is usually within a wider spectrum of assumptions that the child will

ultimately reach expected milestones and achieve independence in adult life. For the parents of a child with learning disabilities, the responsibility for the care of a dependent offspring is ongoing and often lifelong. It is not uncommon for elderly parents to still be caring for their dependent, middle-aged sons and daughters.

The birth of a baby with learning disabilities may require significant adjustments from both the parents and the infant. Part of the initial task of the parents might be to find a way of coming to terms with the loss of the 'hoped for' baby. This process may involve feelings of shock and disbelief and a possible rejection of the baby. Feelings of anger and guilt may be encountered: this might include guilt that one or both parents have contributed to producing a disabled baby or the blaming of themselves or each other for something during the pregnancy that might have caused the disability. There will almost certainly be a search for reasoning and a need to understand why it has happened. During these complex feelings and processes, some parents may find it difficult to be fully psychologically present and available to their child. This potentially presents the infant with considerable difficulties: if we think of Winnicott's idea of the mother's face acting as a mirror in which the child sees his or her own reflection (Winnicott, 1971), the infant with a learning disability may see in its mother's face a complex range of reflections, which may include disappointment and grief. Both may unconsciously withdraw from the pain of the self and the other and healthy attachment might become difficult. From these early beginnings, the child with a learning disability might carry forward into their life some sense of being a disappointment, of being not quite what was hoped for; with perhaps little or no experience of a good primary attachment from which rewarding and enriching future relationships grow, adult life might pose certain potential difficulties.

The next part of this overview will consider the prevalence of self-harming rates amongst the learning-disabled population and will discuss the possible reasons for discrepancies in these statistics. Different methods of self-harm will also be considered.

2.6 Self-harm and learning disability

Writing in the British Journal of Psychiatry in 1998, Collacott estimated that 17.4% of adults with learning disabilities engaged in self-harm, with 1.7% of that population causing severe injuries on a frequent basis. In 2001, Emerson suggested that the rate of prevalence of self-harm in adults with learning disabilities was between 10 and 15%. A little later in 2009, Rojann and Meier estimated that between 4.4% and 21% of adults with learning disabilities were self-harming. It is difficult to account for the discrepancies in these statistics but the studies noted above acknowledge that self-harm is often conducted in private and it can be unclear how these statistics were gathered. If they are based on the number of people presenting at a hospital for medical attention this would not take into account the numbers of people who may be self-harming in private at home. The statistics may also represent different severities of self-harm.

Paley (2008) produced a fact sheet about self-injurious behaviour for the British Institute of Learning Disabilities. It lists the following means of self-harming that may be exhibited by some people with learning disabilities:

- 'face-slapping/striking face and chest with knees
- head slapping, rubbing or banging against surfaces
- trichillotomania (pulling out your own hair)
- self-induced vomiting/vomiting and re-ingesting
- hand-biting
- eating inedible substances (pica)
- eating faeces (coprophagia)'

(Paley, 2008)

It is striking that there is a clear absence of any reference to cutting or burning and this invites some interesting thoughts about whether there is a correlation between the severity of the learning disability and the methods used to self-harm. The choice of method may also depend on what the person has access to. This will be discussed further in §2.6.3. There is also a further question here about terminology: self-injurious behaviour (SIB) or self-harm?

2.6.1 Self-injurious behaviour or self-harm?

When reading articles about self-harm it can seem that a number of seemingly confusing words are used to describe behaviours in which a person deliberately inflicts pain upon their body. The main terms of self-injury, self-injurious behaviour and self-harm can seem to be used interchangeably. Papers suggesting that people with borderline personality disorder and other serious or chronic mental health problems are more likely to use particular methods to self-harm, usually describing methods that are more dramatic, involve blood loss and frequently require medical intervention such as cutting, burning and self-poisoning (Turner et al., 2015; Chapman et al., 2005). Self-harm is often the term of choice for authors and researchers discussing self-inflicted attacks on the body by people with psychiatric disorders. The word 'harm' as opposed to 'behaviour' (in self-injurious behaviour or SIB) might indicate that the act of self-harm is concerned with expressing pain about an unbearable feeling or situation. Conversely it seems to follow that when writing about people with learning disabilities (especially moderate to severe learning disabilities) the term 'self-injury' or 'self-injurious behaviour' is favoured (Duperouzel and Fish, 2007; Taylor, Oliver and Murphy, 2011). The implications of the term 'behaviour' are significant. Behaviour may suggest something that has become integrated into the person's experience and lifestyle. In one paper self-injurious behaviour was referred to as a 'career' (Lovell, 2007); in other words it becomes a defining aspect of the person and what they do. The *Oxford English Dictionary* offers this definition of the term career: 'an occupation undertaken for a significant period of a person's life and with opportunities for progress.' Something undertaken for a significant period of one's life might indeed eventually become a part of what defines that person. For a person with a learning disability, who may not have access to the jobs or careers that others might have, it might nevertheless be important to create a story, a narrative, or a 'career' of their own that offers a sense of self-value and worth. Having an injury that is then sympathetically attended to, might, for some people, confer on them a sense that they are cared for, that people are interested in them and that they matter. If the function of self-harming is self-stimulatory or an attempt to deaden pain (Sandman and Hetrick,

1995), the methods used are likely to be repetitive and ongoing, potentially causing sustained damage over a long period of time.

2.6.2 Self-harm to elicit physical contact

One of the obvious responses that self-harming elicits for the service-user is physical contact, often in response to the need for wound care. Little opportunity exists for physical contact among those adults with learning disabilities who are able to attend to their own personal care needs. People with mild or moderate learning disabilities have the same need for physical comfort, reassurance and affection that anyone might have at times of upset or uncertainty and yet the staff that care for them are constrained by boundaries that do not permit extending physical contact beyond what is professional and necessary. By understanding an ordinary desire for human touch, self-harm can then be seen as a legitimate and understandable way of seeking physical contact, albeit within a medicalised context.

2.6.3 Severity of learning disability and correlation to method of self-harm

As suggested in §2.6.1, there is evidence to indicate that people with a history of mental health problems might engage in more specific forms of self-harm which are often concerned with blood loss and emergency, e.g. cutting or burning the skin and self-poisoning (Turner et al., 2015; Chapman et al., 2005). In my experience, the combination of a learning disability and a co-existing mental health problem does seem to correlate to particular, perhaps more dramatic methods of self-harming that might include skin-cutting and burning the skin. There are, of course, people with moderate, severe and profound learning disabilities who also engage in self-harm, although the methods used may be different. One possible reason for this is the means that people have available to them to self-harm. Often staff may, with good intentions, remove items that could potentially be used to cause an injury, meaning that the impulse to self-harm has to be responded to in different ways. Thus people's patterns of self-harming may change for quite practical reasons.

The BILD suggests various hypotheses for how self-harm might develop in people with learning disabilities and says that:

> 'self injurious behaviour stimulates the production of endogenous opioids, creating an analgesic effect on pain that self-injurious behaviour produces pleasurable feelings and euphoria.'
>
> (Paley, 2008)

Guess and Carr (1991) describe how self-injurious behaviour gradually becomes integrated into the person's experience, beginning with the notion of a child displaying a self-soothing or coping behaviour such as rocking gently. This may be seen as part of the child's learning disability. Gradually these behaviours become self-stimulatory, more intense and gradually more integrated into the person's way of being. Eventually it may develop into self-harming and occupy a more functional part of the person's existence.

2.7 A history of music therapy within a long-stay institution for adults with learning disabilities

2.7.1 Context

This section will consider the historical context in which adults with learning disabilities were cared for before 'Care in the Community' came into being. Considering this and the changes that have occurred during the time that I have been practising as a music therapist has been important in helping to shape the design of this research study: in particular, considering the historical context has emphasised the importance of designing a study in which the service-users' and staff teams' voices were at the centre of the work. When I first started working in this clinical field, twenty-four years ago, adults with learning disabilities were, if not living with their families, traditionally cared for in long-stay learning disability institutions. Reflecting upon my experience of working in a long-stay learning disability institution, I was reminded of how little both service-users and staff were invited to express their thoughts and views, and how life on a busy ward did not allow many opportunities for space and reflection. Accommodation in these institutions often consisted of various bungalows or wards on

a large site, where people with learning disabilities were mainly kept segregated from the rest of society. Many of the people that lived there had done so since early childhood and had little experience of life outside of an institution. Opportunities for choice, independence and autonomy were few and many residents developed complex responses to life in an institution where there was often little expectation of change or development for the people that lived there.

2.7.2 Referrals to music therapy

When I worked in the setting I have just described, the majority of the referrals received by the music and art therapy departments were for patients who were considered challenging by the staff on the wards. The unspoken reason for the referrals seemed to be a (perhaps unconscious) wish from the staff to have a break from those service-users who were considered to contribute to making life on the ward more difficult. Almost all of the referrals to music therapy that I received at this time (the mid-late 1990s) were for those people who were non-verbal and maybe had complex physical needs and challenging behaviour, often described by ward staff in terms of self-harm or aggressiveness towards the staff. The reasons given for referrals to music therapy were frequently concerned with developing communication and self-expression; this might have implied a wish for staff to have a better understanding of the emotional needs of the people they were caring for. This was a part of my thinking when designing the staff group part of the study: providing a space where staff had the opportunity to come to new ways of understanding the emotional needs of the service-users they were caring for and in particular to think about the unconscious reasons why their service-user might self-harm.

On the wards, there was a notable absence of referrals for those service-users who were verbal and seemed, on the outside at least, to be managing life in reasonable ways. It did seem to be the case that those service-users who were able to find some way of externalising their distress were a priority for the staff in terms of referrals to music therapy. Perhaps with better training and a different understanding about the emotional lives of people with learning disabilities it might have been possible to understand that

being verbal and not demonstrating obvious challenging behaviour on the ward may not have necessarily correlated to an absence of emotional distress.

2.7.3 Music therapy provision in the community

The closure of long-stay institutions for adults with learning disabilities also prompted a relocation and redistribution of health service provision. The music therapy department in the hospital where I first worked closed. Following this, health services for adults with learning disabilities were rethought and reconfigured. Geographical areas were redefined and community health teams were established to cover the various group homes within a given boundary. This signalled the move from single-discipline departments into multidisciplinary teams (MDTs). Within our service, two of the newly defined MDTs were actually relocated within the grounds of the original long-stay hospital. This created a rather unusual experience for some patients who, having moved out of a long-stay institution, found themselves returning there for their weekly music or art therapy provision. Referrals were received by the MDT and discussed and allocated at fortnightly team meetings. More recently, the long-stay institution has been sold and within the last few years all the clinical teams and the therapy rooms have been moved out into the community. It is now much more rare for music therapists to have a dedicated clinical space in which to work; instead, sessions are increasingly being offered in rooms in community settings, day centres and regional colleges.

2.8 Carers and people with learning disabilities who self-harm

It is widely accepted that self-harm arouses complex and often negative emotions for care staff and professionals (Hill and Dagnan, 2002; Snow, Langdon and Reynolds, 2007; Duperouzel and Fish, 2007). There are many studies seeking to understand the views and feelings of carers who support people with learning disabilities that self-harm and the result of this research is a much better understanding of the emotional difficulties experienced by staff teams (Hastings and Remington, 1994; Fish, 2000; Gough and Hawkins, 2000; Thompson, Powis and Carradice, 2008; Heslop and Macauley, 2009; Fish and Reid, 2011).

In §1.3 I referred to a study, commissioned by BILD and conducted by Dick et al. (2011), that investigated how care staff understood the reasons why people with learning disabilities might self-harm. The authors suggest that there is likely to be a correlation between the way a carer understood the self-harm and how they responded to it. This study uses Q-methodology as its research method. I have found very little information about Q- methodology; it certainly does not seem to be a mainstream research method. I mention it here because of its similarity to Interpretative Phenomenological Analysis, which is my chosen research method for this PhD research. Developed by William Stephenson (1902–1989), a psychologist and physicist interested in the interaction between psychoanalysis and academic psychology, Q-methodology is a means of analysing data; like IPA, it looks for correlations between subjects within a set of variables and is used in research to examine and understand how people think about a topic. Within the study described above, Q-methodology was used to understand how much care staff across a range of academic backgrounds agreed or disagreed with a sample of statements about the reasons why people with a learning disability might self-harm. Participants were chosen to represent a range of views and the sample covered both qualified and unqualified staff and people of different ages, genders and experience. The hypothesis, which was indeed the case, was that the sample group would represent a broad range of opinions about self-harm in people with a learning disability. Seventy-two statements about the possible reasons why someone with a learning disability might self-harm were identified and the participants were asked to organise the statements according to how much they agreed (+5) or disagreed (–5) with each statement. The results revealed that most people showed some understanding of self-harm as complex, highly personal and emotionally significant to the person. The study showed that staff were mostly responding to self-harm with understanding and sensitivity. However, the study did also reveal a further need for staff training: one of the beliefs held by staff was that self-harm is linked to biological factors; some staff also said that they found self-harm difficult to understand. There were also confusions and misunderstandings within certain viewpoints, which further supports the need for more training. The conclusions from this study were that staff would welcome further support and would like to be able to understand better the complexities arising from supporting service-users who self-harm. Of particular

significance to this PhD research is the recommendation from the Q-methodology study that staff may benefit from a forum through which to express tensions arising from supporting people with a learning disability that self-harm.

The Q-methodology study has yielded some very specific results about how staff understand self-harm in people with a learning disability. From these results, the authors have been able to make suggestions about how these viewpoints might influence the ways in which staff respond to an incidence of self-harm. The study found that there was considerable variation in how the staff perceived self-harm. If the study is also suggesting that there is a correlation between how staff understand it and how they respond to it when it happens, this then invites a question about what a more or less helpful response might look like for the person that is engaging in self-harm. Could there be a correlation between what the service-user perceives as a more or less helpful response and the maintenance of continuing self-harming behaviour?

The authors describe some of the benefits and limitations of the study design: in a Q-methodology study, as with IPA, there is the question of the researcher's own beliefs (their epoché) and how this will influence the selection and interpretation of statements and themes. Q-methodology was appropriate for the BILD study because of its emphasis on finding out what a person thinks about a particular subject; in this case the purpose of the research was to extract the viewpoint of the participant about why somebody with a learning disability might self-harm. Other studies lend support to this theory (Gibb, Beautrais and Surgenor, 2010; Dickinson and Hurley, 2011). Hill and Dagnan, writing in 2002, describe the attributions staff make regarding people who self-harm and how this affects both their emotional and practical responses:

> 'One member of staff may believe that an episode of aggression is mediated by the service-user's lack of verbal comprehension and thus believe that the person has little control over their behaviour. The member of staff may then experience less anger and more sympathy and consequently may strive to communicate at a level more in keeping with the client's perceived level of ability. Another member of staff may perceive the same situation in a different way, attributing the client with the ability to control the aggression, and perceive them as using it as a tool to gain an advantage. The staff member is likely to experience more anger and less sympathy and thus their behaviour towards the client is likely to be very different to that of the first member of staff.'
>
> (Hill and Dagnan, 2002, p. 364)

Snow, Langdon and Reynolds (2007) also suggest that cognitive-behavioural theorists attempting to understand staff responses to self-harm, suggest that the behaviour of care staff is determined by their emotional responses, beliefs and perceptions about self-harm. Another study also concludes that the quality of care that people engaging in self-harm receive is likely to depend on how staff understand the behaviour and their own responses to it (Thompson, Powis and Carredine, 2008). Both studies agree that literature searches in the area of self-harm reveal very few studies relating to the experience of health care professionals and that the existing literature tends to concentrate on the experiences of A&E staff and those working in medical settings. Research carried out by Fish (2000), investigated experiences of care staff working with patients who self-harm within a forensic learning disability service. It concluded that staff felt that relationships with patients were sometimes hostile and involved issues of power, boundaries, risks and control.

The following quotations from other research studies provide evidence for the idea that carers supporting people with a learning disability who self-harm often feel disempowered and stressed:

> 'It is also clear that high staff stress is widespread in services for people with intellectual disabilities. Recent UK surveys of staff in services for people with intellectual disabilities have found that one third of staff report high levels of stress indicative of psychiatric problems.'
>
> (Hatton et al., 1998, p. 270)

Such stresses can have a significant impact on service-users:

> 'High levels of staff turnover have long been recognized as a major problem in services for people with intellectual disability (ID)…such levels of turnover can have serious consequences for service quality. These consequences can be direct in terms of the high proportion of relatively inexperienced and untrained staff working in services, and the lack of continuity in the service provided to people with ID.'
>
> (Hatton et al., 2001, p. 258)

Mitchell and Hastings (2001) studied the links between staff burnout, emotional reactions to challenging behaviour and coping strategies. Staff burnout refers to a psychological condition in which prolonged exposure to emotional difficult situations

leads to a reduced capacity to cope over time. Symptoms of burnout include depersonalisation (expressing negative and impersonal responses to service-users), emotional, physical and mental exhaustion and reduced feelings of job satisfaction and personal value at work. Research suggests that staff who work with people with learning disabilities are at greater risk of experiencing symptoms of burnout with up to a third of staff experiencing stress levels indicative of a mental health problem (Skirrow and Hatton, 2007). Stress has also been linked to negative interactions towards service-users (Lawson and O'Brien, 1994) and increased levels of absenteeism and staff turnover (Hatton and Emerson, 1993; Razza, 1993; Hastings, Horne and Mitchell, 2004). Reasons for staff burnout include organisational factors (Dyer and Quine, 1998) as well as role-conflict, where the demands of the job role conflict with family and other external commitments (Netemeyer, Boles and McMurrian, 1996; Maslach et al., 2001). As discussed in this section, whilst there are a number of studies that aim to understand the views and feelings of care staff that support adults with learning disabilities who self-harm, there is still very little research into how care staff can best be offered support.

2.9 What people with a learning disability find helpful when they self-harm

There is a small number of studies that seek to understand the views of people with a learning disability who engage in self-harming behaviour (Duperouzel and Fish, 2007; Brown and Beail, 2009; Heslop, 2011), and specifically what interventions they experience as helpful and those that are less welcome. These studies use a mixture of semi-structured interviews (SSI) and Interpretative Phenomenological Analysis (IPA) as their research methods. Congruent themes are emerging from these studies; I have summarised these in Table 2.3 below, which shows the title of the research on the left and the strategies that participants in that study found both helpful and unhelpful:

Title of research	Helpful strategies	Unhelpful strategies
Self-Harm Among People with Intellectual Disabilities Living in Secure Service Provision: A Qualitative Exploration (Brown and Beail, 2009)	• Self-talk • Distraction: includes listening to music; talking to staff; going to a calm area; having a sleep; reading • Strategies devised in collaboration with staff or by the service-user	• Any externally imposed interventions from staff • Restraint: includes physical restraint • Removing personal belongings • Being stopped from self-harming • Comments from staff that are experienced as punitive or withholding
Why Couldn't I Stop Her? Self Injury: the views of staff and clients in a medium secure unit (Duperouzel and Fish, 2007)	• Being able to talk about self-harm with understanding staff • Feeling that staff are genuinely interested in the service-user's well-being •Access to a talking space, e.g. psychology • Being allowed to self-harm — it being seen as the service-user's right and choice and for this to be respected	• Feeling misunderstood, judged and controlled by staff • Being questioned about why the service-user has self-harmed • Threats of punishment or increased supervision • Feeling that the subject of self-harm is avoided by staff • Being prevented from self-harming
Supporting People with Learning Disabilities who Self Injure (Heslop, 2011)	• Talking about self-harm • Self-harm acknowledged as an important coping strategy for the service-user • Having a trusting relationship with staff who would be non-judgmental and trustworthy • Staff members who are calm and don't 'flap' • Having a hug • Being offered sensitive support in caring for any injuries • Having some control over self-harming	• Staff avoiding talking about self-harm, leaving service-user feeling punished, judged and misunderstood • Being asked lots of questions if a disclosure of self-harm was made • Being told or encouraged not to self-harm

Tab. 2.3: Helpful and unhelpful strategies

The conclusions from these studies suggest that being able to speak with a member of staff who is trusted to be understanding and non-judgemental is the most supportive intervention for someone with a learning disability who feels like self-harming. Feeling controlled and having restrictive measures placed upon them were experienced as punitive and more likely to increase the impulse to self-harm. All of the studies referred to a preference for either an individual or a collaborative way of responding to the impulse to self-harm rather than interventions that were imposed by staff, which most of the participants across the three studies found unhelpful and controlling. It is worth noting that there were an unspecified number of participants in the Heslop (2009) study who found it helpful to be told not to self-harm. This conforms to a consensus that self-harm is highly personal to the individual; therefore ways of understanding and responding to it need to take into account the needs and preferences of the person engaging in it.

Themes emerging from all three of these studies include the desire for further training that offers staff specific counselling skills and other practical strategies for supporting people when they self-harm. Staff frequently refer to a lack of training and many experience difficulties in managing and understanding their feelings when confronted with self-harm. They may work in a context where they are expected to prevent people from self-harming; this may lead to a culture of blame where staff may feel guilty when a service-user self-harms and fear being held responsible for not preventing it. This burden of responsibility complicates the already complex issues of power and control that might unconsciously be being played out between service-user and staff when a service-user self-harms. Questions of guilt arise if the service-user imagines that a member of staff might be held accountable if they self-harm, or that the staff member would be upset to see the service-user injure themselves. But within a context where it is expected that self-harm will be prevented as far as possible, and with little supervision or training being offered, staff report feeling forced into a '"power struggle" where self-harm, no matter how minor, is experienced by staff as a failure' (Duperouzel and Fish, 2007, p. 64).

2.10 Scientific justification for the research

This research project acknowledges the challenges for adults with learning disabilities who self-harm and the staff teams that support them. Through an investigation of the literature, I have made a case for the need to provide service-users with access to a therapeutic space where the motivation to self-harm can be explored, painful feelings can be expressed and trauma can be processed through words and/or improvised musical exchange. The case has also been made for staff teams to have a means of expressing their feelings about supporting learning-disabled people who self-harm. The current literature in the field of learning disabilities and self-harm shows care staff frequently asking for more training and support in order to make helpful and thoughtful responses to the people they care for when they self-harm. A staff support group that can acknowledge the staff's feelings and concerns, and can discuss the ways in which the service-user's self-harming impacts upon them as a staff team, can potentially come to new ways of understanding self-harm and its meaning.

2.10.1 The gap in the literature

Self-harm among people with learning disabilities invites speculation about its meaning and purpose for the person engaging in it. As discussed in §2.8, self-harm is complex and can present particular challenges for those who engage in it and the staff teams that try to offer support. In her book *Mental Handicap and the Human Condition*, Valerie Sinason says:

> Too often, unsupported workers, despairing over such clients' chronic self-destructive attacks, give up trying to understand what is happening. Faced with six clients who knock themselves out by the extent of their headbanging, they might find it easier to think that it is due to the handicap rather than consider that each act has its own inner meaning.
>
> (Sinason, 1992, p. 222)

Whilst offering music therapy to somebody who self-harms has been written about (Lawes and Woodcock, 1995; Ford, 1999), as the literature search has revealed, there is much less thinking about how the needs of the staff are attended to and no examples of a music therapy intervention for the service-user alongside a simultaneous, separate

intervention of any kind for the staff team. The literature discussed in Chapter 2 that studies staff teams that support people with learning disabilities who self-harm (Hill and Dagnan, 2002; Snow, Langdon and Reynolds, 2007; Duperouzel and Fish, 2007 and also Hastings and Remington, 1994; Fish, 2000; Gough and Hawkins, 2000; Thompson, Powis and Carradice, 2008; Heslop and Macauley, 2009) identify that staff teams are requesting support but do not go beyond acknowledging and identifying that need. The literature search has not revealed any actual interventions for staff in which the complex feelings arising from supporting a service-user with learning disabilities that self-harms can be addressed. Therefore this research study investigates a gap in knowledge about what meaningful support can be offered to staff to enhance understanding and facilitate improved relationships between service-users and support staff. This research study will also add to the very small body of literature that investigates the effectiveness of music therapy for learning-disabled adults who self-harm. The two interventions together investigate a gap in the literature about attending to service-users and staff teams simultaneously.

Chapter 3: Research Methodology

This chapter will discuss the research design, the methodology and the research questions that have arisen from a consideration of the literature discussed in the previous chapter. It will also discuss the rationale for choosing a qualitative design and for analysing the data generated through an IPA (Interpretative Phenomenological Analysis) framework. This is a qualitative study: the rationale for choosing this method over other possibilities is discussed in §3.2 and §3.3. Qualitative research invites questions about the researcher's personal bias and assumptions; it examines the interaction between the phenomena under investigation and the beliefs and perceptions held by the researcher about the subject under consideration. Therefore my epoché, a consideration of my personal assumptions and reflections in relation to music therapy practice, will also be described here. This chapter includes the design of the participant information sheets, with both text and widgit symbols, the method of devising the semi-structured interviews for this study and the ethical considerations and process for gaining full ethical approval. The psychoanalytic concepts that underpin my music therapy practice will also be described here. Whilst this chapter discusses the overall rationale for, and design of the study, the method chapter (Chapter 4) will describe in a more specific way, the steps taken to carry out this research study.

3.1 Research questions

The principal research question that this study seeks to investigate is:

- Does the combined approach of weekly music therapy for the learning-disabled service-user who self-harms and a monthly support group for the staff team correlate to a reduction in the number of incidences of self-harm?

The secondary research questions are:

- Does staff's attitude change in relation to supporting adults with learning disabilities who self-harm as a result of attending regular staff groups for themselves?

- Does staff's understanding about the nature and impact of self-harm increase?

3.1.1 Defining the research questions

The principal research question is concerned with any reduction in the number of incidences of self-harm across the timescale of this research study. I am interested in investigating whether there is a link between the provision of weekly music therapy for the service-user and the monthly support group for the staff teams and a reduction in self-harming.

Change was measured numerically, i.e. by studying the number of incidences of self-harm. This information was generated by behaviour reports kept by the staff to report any challenging behaviour or reports of self-harm for all residents in the house. These records are part of the care home's own recording systems and are the method by which the staff homes collected and recorded this information independently of this PhD research study. The two staff teams in this research study had different ways of recording information about their service-users, including any episodes of self-harming. This seemed to reflect a difference in the working practices of a staff team dedicated to one house and the people who live there, as opposed to a community support team where the staff had a large number of people in the community to visit and attend to. This reflects the arrangements for Derek and Janet respectively. Whilst Derek's staff team were usually able to keep note of incidences of self-harm as they unfolded, for Janet's staff team this was often much more challenging owing to the nature of community work and the extreme time pressures. Therefore, because of the differences and discrepancies in the two staff teams' note-keeping, I decided not to include numeric information from their records. In the SSIs, staff consulted their own logs which acted as a secondary source of evidence; therefore these reported reductions of the incidents of self-harm were considered valid.

In the semi-structured interviews, staff groups were asked for the number of incidences of self-harm that their service-user had engaged in over a four week period. For the service-users in this study, a time period of that length may have presented difficulties in remembering the number of incidences, so a shorter period of one week was selected. As will be discussed in §4.4.1, this was felt by speech and language therapy colleagues and service-users involved in the study design to facilitate a more reliable data collection. Both service-user participants were able to accurately comment on the number of times they had deliberately harmed themselves within a seven-day timescale; this was confirmed by members of their staff team.

Of the two secondary research questions, the first asks about changes in staff attitude relating to those times when the service-user they support engages in self-harm. These changes were understood by:

- How the staff spoke about self-harm during the staff support groups: the language used; the body language of the staff; the way self-harm was described; what staff members' opinions were about self-harm and what they thought self-harm meant for the service-user. I was interested in whether views and perspectives changed over the twelve staff support groups received as part of this research study.

- How the staff responded when the service-user they support self-harmed and whether or not the staff had a cohesive whole-team approach to which all members of staff adhered, regardless of which individual staff member was attending to the service-user.

- Whether the response to an incident of self-harm differed at the end of the study from how it was at the outset.

This data was generated through the semi-structured interviews for the staff teams across the timescale of the study.

The final question I am interested in is how staff understood self-harm and what the implications of this were on their response to the service-user they support. Unlike the previous secondary research question, where change was measured through practical responses to self-harm, this question is more concerned with how staff understood, rather than what they actually did. Data was again collected through the semi-structured interviews and the monthly staff group meetings. Change was measured through analysing how the staff talked about self-harm during the staff support groups, the language they used, the way self-harm was described and what staff members' opinions were about self-harm. Change was also measured through the SSIs. This was considered over the timescale of the twelve staff support groups and the three SSIs that the staff team received as part of this research study. Change for the service-user was measured through both the SSIs and the content, both verbal and musical, of the music therapy sessions. Therefore, all of the weekly music therapy sessions for the service-user and the monthly groups for the staff teams were recorded and listened to and helped to inform the analysis.

3.2 The study design

This section will consider the rationale for choosing a qualitative study design over the other possible study designs that music therapy researchers might employ. Considering research inevitably leads to a question of clinical practice, particularly the interaction between music therapy practice, theory and emerging research questions. My research questions for this PhD study initially arose from an increasing number of referrals to the MDT for adults with learning disabilities with a chronic history of self-harm, as well as the difficulties encountered by the staff teams that care for them. This led to a consideration of the psychoanalytic theories that underpin my music therapy practice, as well as group analysis theory (discussed further in §3.7), each of which helped to shape and define the final study design. Gaston (1968) suggests that the dimensions of clinical practice, theory and research form an interdependent tripod, each leg of which is equal in importance and necessary for the others to stand. Bruscia (2005) is also interested in the interaction between these dimensions:

‘Theory has a central place in music therapy — it shapes and is shaped by practice and research. Regardless of whether the theory has been clearly articulated by the therapist or theorist, theory provides a foundational structure for all clinical work. Conversely, practice is often the basis upon which a theory is developed. Similarly, research may be the foundation for theory, or it may be the result of theory.’

(Bruscia, 2005, p. 540)

3.3 Interpretative Phenomenological Analysis (IPA)

The word phenomenology originates from the Greek *phainómenon*, meaning ‘that which appears’ and *lógos*, meaning ‘study’. It is the philosophical study of the structures of experience and consciousness. A fundamental tenet of phenomenology is the idea of intentionality (Smith, 2008, p. 6), which, in this context, refers to consciousness. According to Giorgi and Giorgi (2008, p. 33), Husserl suggests that ‘what every person is present to is the world or some aspect of it’; this suggests that each person is present to some aspect of the world and the question is how best to communicate about such objects of consciousness or experiences. IPA explores how people make sense of their social and personal worlds and studies the particular meanings that certain experiences have for people. It is concerned with obtaining a detailed account of how somebody experiences a particular phenomenon and is about the person’s own experience and perception of it. IPA also acknowledges that research conducted within this framework is a process which therefore takes into account the researcher’s own perceptions and beliefs. Smith and Osborn (2008) describe this as a dynamic process on to which the researcher’s own thoughts and ideas impinge:

‘One is trying to get close to the participant’s personal world…but cannot do this directly or completely. Access depends on, and is complicated by, the researcher’s own conceptions; indeed, these are required in order to make sense of that other personal world through a process of interpretative activity.’

(Smith and Osborn, 2008, p. 53)

Writing in 1990, van Manen describes phenomenology as:

‘systematic in that phenomenology uses a practiced mode of questioning, reflecting and focusing; explicit in that it articulates the meaning embedded in the lived experience; self-critical in that it continues to examine its own goals and methods; intersubjective in that it needs

co-researchers to develop a dialogue relationship with the phenomenon, and thus validate the phenomenon; and a human science in that the subject material is always human experience.'
(van Manen, 1990, p. 323)

A richly detailed IPA analysis can involve the researcher analysing the text and questioning the meaning behind the words: in other words, considering what might unconsciously be occurring beyond what is being reported verbally:

'IPA has a theoretical commitment to the person as a cognitive, linguistic, affective and physical being and assumes a chain of connection between people's talk and their thinking and emotional state…the researcher has to interpret people's mental and emotional state from what they say.'
(Smith and Osborn, 2008, p. 54)

This interpretative aspect is an important part of this process, which is why the researcher needs to be as conscious as possible of his or her own beliefs, assumptions and biases in relation to the phenomena under investigation. The consideration of the researcher's perceptions and beliefs will be discussed more fully in §3.3.3 where my epoché will be described.

3.3.1 Qualitative research

Qualitative research considers the interaction between the phenomena under investigation and the researcher's own ideas, perceptions and assumptions about the matter being studied. As discussed in §3.3, in order for the study to be as free as possible from the projections of the researcher's biases, it is advisable for these biases to be examined and brought into consciousness as far as possible. Therefore, it has been important for me to consider my perceptions and judgements relating to music therapy, learning disability, staff teams and self-harm and the ways in which these might influence my interpretation of the data generated by the participants about their own lived experience. This process is often described as the researcher's epoché or examination of personal assumption and bias. A brief examination of the phenomenological epoché and how it came to find its prominence and significance in social research will help to place the epoché in its historical context.

3.3.2 Phenomenological epoché

Phenomenology seeks to create a context for the examination of human experience that is free from judgement, assumption, emotion and the beliefs and perceptions of the investigator. Its founder, Edmund Husserl (1859–1938), a German philosopher, suggested that:

> '…only by suspending or bracketing away the "natural attitude" could philosophy become its own distinctive and rigorous science, and he insisted that phenomenology is a science of consciousness rather than of empirical things.'
>
> (Sawicki, n.d.)

Finlay quotes Husserl's "rallying cry, **'*Zu den Sachen selbst!*'** ('Back to the things themselves!')" (Finlay 2011, p. 3) and he says that Husserl "exhorted phenomenologists to go all out to capture the richness and ambiguity of the 'thing'' (Finlay, 2011, p. 3).

Husserl used the term 'phenomenological epoché' to describe the procedure by which judgements about a general or philosophical belief are suspended in order that phenomena can be examined in their purest and most original state. In phenomenological research, biases, assumptions and personal perceptions are blocked as far as possible in order that the matter under examination can be explored in terms of its own inherent meaning. The undertaking of any phenomenological research therefore requires a certain predisposition in the researcher towards a capacity to withhold judgement and set aside personal bias. An examination of the investigator's personal bias and assumptions is therefore necessary.

3.3.3 My epoché

Since qualifying as a music therapist in 1995, there have been a number of influences on the development of my clinical practice. These influences have taken place against a background of receiving my own regular psychotherapy and clinical supervision. I have been fortunate enough to have received supervision from several different practitioners ranging from analytic psychotherapists to arts therapists of differing modalities. Each

have brought their own theoretical influences to the supervisory encounter and have helped to shape my own clinical and supervisory practice.

My clinical work has been exclusively in the field of adult learning disabilities and psychotherapy and supervision have both been useful in examining my reasons, both conscious and unconscious, for this choice of career. Personal therapy, in particular, has been a place to examine my own assumptions and beliefs about my motivations for working as a music therapist in this area; by making these personal perceptions and biases more conscious it has helped me to become more aware of them and to understand how they impact upon my clinical practice. Personal therapy has also allowed a space to reflect on my own limitations and potential as a music therapist. I have also been supervising music therapy students and qualified music therapists working in the fields of learning disability with adults and children for over twenty years. This includes hosting student placements within my place of work, as well as private individual and group supervision. I have also supervised other, non therapy, colleagues within the National Health Service. I find it inspiring and challenging to work with students, music therapists and other colleagues and these opportunities provide the chance to reflect on my own clinical practice as well as the parallel processes between both the therapeutic and supervisory encounters.

Outside of music therapy practice, I have an active life as a pianist, musician and piano teacher. I regularly perform as a chamber musician, mainly as part of a piano duo but also as a piano accompanist and singer in a chamber choir. This part of my life pre-dates my practice as a music therapist and therefore has been and continues to be hugely influential. Interestingly my musical life has developed into something that is increasingly collaborative and whilst I very much enjoy playing as a solo pianist, my greatest pleasure comes from collaborations with other musicians. This also has resonances to my interest in groups which extends to the areas of both music and therapy.

Shortly after qualifying I undertook a year of training in group work. This involved attending lectures about group analysis, theory and practice, participating in an

unstructured large group and attending a small therapy group. Several years later I did a further year of training in systemic family therapy. Both courses developed my enjoyment of working with groups and I became interested in the unconscious dynamics that are played out when a group of people come together in both structured and unstructured ways. There are obvious parallels with life as a musician, especially in terms of performing with other people as a chamber musician with all its possibilities for initiating, following, improvising, listening and responding.

These ideas, present so obviously in musical encounters, have also weaved through other aspects of my work, including giving conference papers and writing book chapters and reviews. These activities, with their requirements to initiate ideas, improvise (when speaking about one's work), listen and respond (to other literature when writing one's own work, for example) have all helped me to develop both a critical and reflective approach to my work. I enjoy working in a detailed and analytical way and so the idea of qualitative research and working on a small-scale single-case design in rich detail was very attractive to me.

3.3.4 Single-case design

This research project uses a small, qualitative single-case design. A single-case design study involves the intensive description and analysis of a person over a period of time. The subject acts as their own control, meaning that there is not a control group with which to make comparisons. Instead, the subject acts as an independent variable and the research centres on the behaviour of that person under varying conditions, in this case, before and during a music therapy intervention. Single-case design methods typically involve gaining a baseline assessment to determine current behaviour before any intervention is offered and then gaining further assessments during the treatment and afterwards. Shaughnessy et al. (2012) describe the ABAB design:

> ‘to demonstrate that behavior changes systematically when they alternate “no treatment” and “treatment” conditions. An initial baseline stage (A) is followed by a treatment stage (B), next by a return to baseline (A), and then by another treatment stage (B). Because treatment is removed during the second A stage, and any improvement in behavior is likely to be reversed at this point, this design is also called a reversal design.’
>
> (Shaughnessy, Zechmeister and Zechmeister, 2012, p. 296)

The authors suggest that there are important ethical considerations concerning the withdrawal of treatment, especially if the intervention is having a positive benefit to the recipient. This dilemma, they argue, may prevent psychologists from using this design. Interestingly, and in resonance with this PhD research, the example they give is of a child with autism being offered an intervention to reduce self-injurious behaviour. The intervention offered was having a positive effect, leading the authors to determine that it would be unethical to withdraw the treatment. To address this dilemma, the authors offer an alternative study design: the multiple baseline design. By establishing several baseline designs, this study design allows the effects of treatment to be shown across different baselines as treatments are introduced. Due to the nature of the phenomena under investigation in this PhD study and the possible narratives that might emerge in music therapy about the participants’ motivations to self-harm, it did not seem in the best interests of the service-users to withdraw this intervention once they had engaged in this process. For the purposes of this study baseline measurements were taken by means of semi-structured interviews for care staff and service-users before any intervention was offered, in order to determine current frequency and patterns of self-harm and staff responses to it.

3.3.5 Sample size in IPA studies

IPA studies use small sample sizes due to the richness of the data being generated and analysed. ‘Richness’, in the context of qualitative research, refers to the complex, in-depth analysis carried out, which generates highly detailed ‘rich’ or ‘thick’ data. The aim is to convey detailed information about the person’s perceptions and understanding of the subject under investigation, rather than offering a more general overview. These differences, a broad, generalised view and a detailed analysis, can be defined by the

terms nomothetic and idiographic. First described by the philosopher Wilhelm Windelband (1848–1915), these terms describe two distinct approaches to knowledge:

- 'nomothetic: described as a tendency to generalize, and is typical for the natural sciences. It describes the effort to derive laws that explain *types* or *categories* of objective phenomena, in general.
- idiographic: described as a tendency to specify, and is typical for the humanities. It describes the effort to understand the meaning of contingent, unique, and often cultural or subjective phenomena.'

<https://en.wikipedia.org/wiki/Nomothetic_and_idiographic>

A nomothetic study may, for example, be analysing groups and populations and making claims about outcomes based on probability and percentages. An ideographic study can make more specific claims based on a detailed analysis of individual case studies. Sample sizes can vary considerably and, according to Smith and Osborn, published IPA studies exist with samples ranging between one and fifteen (Smith and Osborn, 2008, p. 56). They discuss the recent trend of conducting IPA studies with very small numbers of participants: the reason for this acknowledges the painstaking work of analysing data to produce a detailed interpretative account of the participant's experience, which for many researchers is only realistic if the sample size is small. My own sample size considerations are discussed further in §3.9.1 and §8.3.3.

3.3.6 Gathering data in phenomenological research

As this section has shown, IPA is a useful research method to use for gathering information in order to understand how individuals perceive a certain situation or experience. A common method of gathering data in phenomenological research is through the use of interviews, particularly the semi-structured interview (SSI). This style of interviewing allows for a dialogue between the researcher and the participant. Questions will be more flexible than they would be for a structured interview, where the questions would be short, specific and read exactly as written on the interview schedule. Semi-structured interviews allow the interviewer to respond flexibly to the respondent's interest or concerns. As participants describe their experience, the interviewer may seek further clarification and understanding about their feelings at the time of the experience

or try to find out more detail about what took place. The aim is to gather as full a description as possible. When considering the possible ways of gathering data, I also examined the method of using focus groups as an alternative to SSIs.

3.3.7 Focus groups

Focus groups bring together a diverse population and aim to capture the interactions between the participants based on their responses to a topic provided by the researcher. Importance is attached to the participants having specific experience or opinions about the topic under investigation, with the purpose of the focus groups being to evoke the attitudes, feelings and beliefs of the participants about the subject. Whilst there are overlaps between the methods of focus groups and SSIs to extrapolate the views and perceptions of the participants about a given topic, the differences between these two methods considered in relation to my research questions led me to select the use of SSIs over focus groups. Both focus groups and SSIs allow many voices to be heard at once and also facilitate group discussion based around a set of questions or an interview schedule. Both attend to the group as a whole rather than individual interviews and promote and encourage interaction between the participants. Focus groups can also be used to brain-storm and generate new ideas about the subject under investigation whereas SSIs are interested in understanding the current, lived experience of the phenomena under consideration, as experienced by the participants, in this case supporting a learning-disabled person who self-harms. The aim of the SSIs was not to necessarily generate new ideas (although the staff may come to new ways of understanding and responding to self-harm as a result of participating in the monthly staff groups) but rather to be able to reflect upon their experiences as they currently stand. SSIs allow for a greater level of detail due to the nature of the interview schedule, which is the same at each interview and also involves the researcher as part of the process. It is often the involvement of the researcher/interviewer and the strength of the alliance between them and the participants which facilitates more detailed descriptions of their lived experiences of the phenomena under investigation.

3.3.8 Ferrara's method: applying phenomenology to the analysis of music

Another way in which phenomenology is used within music therapy research is to analyse the music generated within a music therapy session. Whilst IPA can be thought of as a framework for understanding the ways in which people articulate, usually verbally, something about their lived experience of the subject under investigation, the musicologist Ferrara expanded this to develop a structure for understanding and analysing a piece of music. Ferrara suggested a five-stage process for analysing a piece of music. It is paraphrased here by Forinash and Grocke, writing in Wheeler (2005):

> *Open listening-subjective response:* On the first listening the person writes down the subjective response, including any impressions that stand out;
> Listening for syntactical meaning — describing the sound as it is heard: In this stage the listener writes down all the musical sounds that are heard, including instruments, embellishments, dynamic changes, melodic, rhythmic and harmonic features;
> *Listening for semantic meaning:* On the third hearing the listener describes what the meaning of the music is thought to be, what mode it suggests and how the listener feels;
> *Listening for ontological meaning — the lifeworld of the composer:* In the fourth hearing the listener puts the music into the lifeworld of the composer and tries to understand what the composer is saying;
> *Open listening — the meaning dimension of all the hearings of the music:* In the final stage of listening, all the impressions and perceptions from the previous four hearings are synthesised and integrated to create a final description of the work.
>
> (Forinash and Grocke, in Wheeler (ed.), 2005, p. 324)

Various music therapists have adapted Ferrara's methods and used them within IPA research. These will be discussed in §3.3.9. I did consider analysing the music generated during the service-user's music therapy sessions and would like to develop this in future research. For the purposes of this study, I decided not to analyse the music because, although this would have been very interesting, I was mindful of the time demands in analysing both music and transcripts. However, I acknowledge the importance of phenomenology in the music therapy profession and there follows some examples of its impact in this field.

3.3.9 Music therapy and IPA

Phenomenology first entered the music therapy profession in the early 1980s. Ferrara's work has been very influential in the field of music therapy and a number of music

therapists have used his methods in their research (Ruud, 1987; Forinash and Gonzalez, 1989; Arnason, 2002; Trondalen, 2003). Forinash and Gonzalez adapted Ferrara's method to study the experience of music therapy for a patient at the end of life in a hospice. Arnason has developed Ferrara's approach and applied it to listening to group improvisations. Ferrara's work and the research of those who have adapted his methods offer music therapists new ways of hearing and understanding the improvised music that is generated within music therapy sessions.

3.4 Semi-structured interviews (SSIs)

This section will discuss semi-structured interviews as the main method of generating data for this research project. Two different questionnaires were devised, one that was used with care staff and the other with service-users. The reasons for using different questionnaires will be discussed in §3.4.4. These questionnaires formed the basis of the SSIs. The SSIs were transcribed in full and from these transcriptions data pertaining to the research questions was extracted. Each music therapy session and staff group was recorded and listened to and this provided additional information, but the SSIs provided the majority of the data for this research.

3.4.1 A brief history of the semi-structured interview

The earliest known example of a semi-structured interview took place in the 1880s when Charles Booth conducted a study looking at poverty in London. Interviews were carried out in a poverty-stricken area of the East End of London with School Board Visitors (SBVs). The SBVs were allocated households for which they were responsible; in the event of non-attendance at school the SBV would visit the family in order to establish the reasons for absence. This information was gathered by means of interviews with the parents. The severity of poverty was a significant factor in determining school attendance and the SBVs often built up a close relationship with the families with which they were involved. Booth undertook extensive interviews with the SBVs in order to understand in detail the experiences of the households affected by acute poverty. Platt (2001) states that:

> ‘The personal interview is penetrating; it goes to the “living source.” Through it the student…is able to go behind mere outward behaviour and phenomena. He can secure accounts of events and processes as they are reflected in personal experiences, in social attitudes. He can check inferences and external observations by a vital account of the persons who are being observed.’
>
> (Platt, 2001, p. 11)

Various types of interviews, including structured, unstructured and semi-structured, have been considered for this study, but I will describe the semi-structured interview in more detail and outline why I think it offered the best way of gaining information for this study.

3.4.2 The semi-structured interview (SSI): advantages and disadvantages

3.4.2.1 Advantages of the SSI

Semi-structured refers to an interview that is based on a series of questions, but also allows, to a certain extent, the respondent to digress and meander. The interviewer is at liberty to prompt and seek clarification or expansion in order to gain as in-depth an understanding as possible of the interviewees’ experience of the subject. The interview may focus more on a theme rather than a precise question and the purpose of the semi-structured interview is to obtain as much rich data as possible about the phenomena in question. The interviews are recorded and transcribed verbatim. Marshall and Rossman (1995) compare the qualitative interview to a written questionnaire and conclude that the alliance that can be formed between the interviewer and the respondent can facilitate the interviewee to share information that may be sensitive or personal. In this study the staff groups often found it difficult to articulate their ambivalent feelings towards their service-users, especially when they self-harmed; certainly the formula of a conversational interview allowed some of these more uncomfortable feelings to emerge. The flexibility of the semi-structured interview, allowing for diversion, expansion and clarification, is one of the greatest advantages of this method of interviewing. It allows the interviewee time and space to describe their personal experience of the phenomena under investigation:

> ‘In contemporary society the way people live their lives, the issues they face, their experiences and how they see and make sense of the world are extremely varied and not necessarily evident to the researcher…The interview gives the researcher access to interviewees’ thoughts, reflections, motives, experiences, memories, understandings, interpretations and perceptions of the topic under consideration. It gives the researcher the opportunity to establish why people construct the world in particular ways and think the way they do.’
>
> (Morris, 2015, p. 5)

For the purpose of this research, I want to understand in detail how the staff teams experience caring for somebody with a learning disability who self-harms. Within a staff team there are individuals each with their own views, motivations and understanding of the service-user that they support, but for this research study, I decided to interview the staff team as a group. The justification for this, rather than interviewing each member of the staff team separately, was to gain insights into how the staff functioned as a team. By conducting a group interview it established the staff team as a single entity, thinking and working together to support the service-user. It acknowledged them as a team to which each person individually contributed. Within the MDT where I work, there have often been instances where challenging behaviour, including self-harm, can be very divisive for staff teams. Offering semi-structured interviews to the staff as a whole team provided opportunities for the team to share experiences and acquire a better understanding of how they functioned as a cohesive team.

3.4.2.2 Disadvantages of the SSI

One of the main disadvantages of the semi-structured interview method is its reliance on the honesty and integrity of the interviewee. In its simplest terms, an interviewee is at liberty to express any view and the interviewer has limited means for checking its authenticity. Obtaining accurate data therefore becomes an important consideration. A factor that may help to mitigate against this is the quality of the alliance that can often be formed between the interviewer and the interviewee, which, if supportive and comfortable, is more likely to facilitate a more honest account of the participants’ reflections and experiences. Conversely, it could be argued that interviewing the staff team together may have prevented some staff members from speaking openly about some of their more hostile or ambivalent feelings towards each other and the service-

user they supported. Interviewing the staff team together could also be a potential advantage of the semi-structured interview; the potential for learning about how the staff functioned as a team being one way to address the secondary research questions: did staff's attitude change in relation to supporting adults with learning disabilities who self-harm as a result of having regular staff groups for themselves? Did staff's understanding about the nature and impact of self-harm increase as a result of participation in this research?

Implications of cost and time are further disadvantages of this method. It can take considerable time to set up interviews, especially when interviewing a staff team. The transcription verbatim of many hours of interviews is also very time-consuming or costly should such a service be paid for.

3.4.3 Boundary considerations in undertaking the SSIs

My researcher role within this study existed across multiple levels. These included project designer, researcher, music therapist, data collector and data analyst. It has therefore been important to give due consideration of how best to manage the complex boundaries that might arise from these multiple roles. The result of these considerations was the appointment of two staff group facilitators (SGFs) to facilitate the monthly staff reflection groups, thereby enabling appropriate therapeutic boundaries and ensuring confidentiality between the individual music therapy sessions (which were carried out by me) and the monthly staff groups. Clinical supervision was available to further facilitate the integrity of these boundaries.

I conducted the SSIs for both the service-user and the staff team, in my role as the researcher for this study. Making this decision gave rise to some boundary considerations due to my dual role as both researcher and clinician. I considered appointing a research assistant to conduct the semi-structured interviews and there would have been benefits to this: from a boundary point of view, it may have provided greater clarity, particularly in terms of the service-user with whom I had another role as the music therapist conducting the sessions. The boundary issue of me conducting the

SSIs for the staff team did not seem problematic as the monthly staff groups were facilitated by an SGF, so there was no conflict of boundaries. In terms of the SSIs for the service-user this was more complex and it might have been preferable to have had a different person doing this from the person conducting the weekly music therapy sessions. The decision to act as both clinician and interviewer for the two service-users participating in this study was arrived at because both participants can be quite anxious about meeting new people. Although, when first approached about the study, they were keen to find out more about it, both were quite reserved at the initial meetings and their staff teams described them both as needing time to get to know new people before feeling confident about 'opening up' to them.

One of the main benefits of the use of SSIs to gather data, particularly about a person's lived experience of the phenomena being investigated, as discussed in §3.4.2.1, is the quality of the alliance and the trusting relationship than can be built between the interviewer and interviewee. This can be one of the most significant protective factors against dishonest or unreliable data; if the interviewee feels he can trust the interviewer, he is more likely to feel able to be open and honest in expressing thoughts or ideas that might be negative or controversial. This, alongside the difficulties I knew the two participants had in meeting and feeling comfortable with new people, led me to think that any potential conflict of boundaries would be outweighed by the participants feeling less anxious by being interviewed by somebody familiar. This had the benefit that more reliable data would be generated than if the participants had been interviewed by someone they did not know, where it was considered by the staff teams that knew them that the participants would be more reluctant to talk freely. The issues of boundaries and researcher bias will be discussed further in §8.3.4, §8.3.4.2 and §8.3.4.3.

3.4.4 Use of semi-structured interviews for service-users and care staff

It was necessary to use differently worded semi-structured interviews for the staff team and the service-users that participated in this study in order to make the interviews meaningful for both. The topic guides for the SSIs are discussed in §4.4.2 and §4.4.3.

For the service-user SSIs, I consulted with speech and language therapy colleagues about appropriate language for the individual service-users who were recruited to the study. It was felt that neither of the participants required the use of any widgit symbols or Makaton signs as the SSI would take the form of a conversation and not a questionnaire. Both participants were felt to be able to manage a conversational style of interview and both gave their consent for this. The service-user SSIs invited the participants to say something about their experience of self-harm: how often they self-harmed; what methods of self-harm they used; how it made them feel afterwards; how the staff responded to them when they self-harmed and whether or not they found the staff's interventions helpful. Participation in the research study lasted for a year. Three semi-structured interviews were conducted: the first at the start of the research study, before any intervention had been offered; the second after 6 months and the third at 12 months (at the end of the study). The second and third SSIs invited the service-user to say something about their experience of music therapy. This was not mentioned in the first SSI as the service-user would not have received music therapy at this point.

The SSIs for the staff also sought information about the frequency and method of self-harm and what the staff would like to have changed. The staff teams were also invited to think about how they understood the service-user's self-harming: did they understand why the person might have self-harmed at a particular time? Did they have a sense of the service-user's emotional state before the incident of self-harm took place? What was their own emotional response to the service-user's self-harm: did they feel manipulated, angry, sad, helpless, disgusted, for example? How did they respond when presented with a deliberate self-injury? The semi-structured interview conversation allowed for an acknowledgement that self-harm can evoke many strong emotions in care staff, some of which may feel quite negative, and that this is borne out in other research studies (Moores, Fish and Duperouzel, 2011; Usher, 1994).

Once full ethical approval had been granted, I was able to begin recruiting to this study. Recruitment will be discussed further in §3.5.3 and §4.2.1. Following recruitment to the study, semi-structured interviews took place prior to any treatment. This allowed for

a base-line measure to be obtained from which any changes could be discerned. The SSIs were recorded and transcribed verbatim.

3.5 Participation in the research study

This next section will consider how the participants came to take part in this research study. Inclusion and exclusion criteria will be described and there will be a consideration of how consent was obtained. The processes for both recruitment and ethical approval are also discussed.

3.5.1 Ethics

Once the study design was completed, I was able to begin the process of seeking ethical approval. Gaining full ethical approval that allowed me to begin recruiting participants to this study was a lengthy and complicated process. It required gaining ethical approval from both the University and the NHS before applying to my local Health Research Authority (HRA) for approval from a local Research Ethics Committee (REC).

When the HRA considers the application to be valid and confirms that it has the required information for the application to be debated and assessed more fully at a REC review panel meeting, the application is forwarded to either the applicant's most local REC or one that next convenes at the most convenient time for the applicant. The role of the panel is to 'safeguard the rights, safety, dignity and well-being of research participants independently of research sponsors' (www.hra.nhs.uk).

My application was made via the Integrated Research Application System (IRAS), by completing an IRAS form. The REC panel identified a few small points which required further clarification. These were to do with gaining informed consent and the panel asked for clarification about how I was going to present the information sheets to participants with learning disabilities. I was asked to make some minor amendments and resubmit some of the IRAS form. The changes and re-submission to ethics will be

discussed in §3.5.5, §3.5.6 and §3.5.7. Following resubmission with minor amendments, the project was granted full ethical approval from the Health Research Authority in July 2015, with permission to begin recruiting to the study.

3.5.2 Criteria for participation

Participants in the study were men and women with learning disabilities in the mild to moderate range who regularly self-harmed and were aged between 19 and 65 years. Also included in the study were members of the staff teams who supported the service-users on a daily or regular basis. I did not want to be too prescriptive about how frequently somebody needed to self-harm in order to fulfil the criteria for inclusion in the research. The critical factor was that the frequency of self-harm was significant enough to be adversely affecting the person's life and the service-user wanted to reduce their self-harming.

All participants had to be able to give informed consent to participate in the study. This meant that they had to be able to understand all the information presented: what the study was about; what involvement in the study would mean; whether there were any risks or benefits to participation as well as understanding their right to withdraw from the study at any time without their care or service being compromised in any way.

The exclusion criteria meant that people could not participate in the study if they had received music therapy within the past five years, either with me or with any other music therapist. Exclusion criteria also ruled out people who were not able to understand the participation information sheets and were therefore deemed unable to give consent. This was determined at the stage where the researcher presented the participation information sheets to the potential participant in the presence of a staff member. The method for administering this, and determining whether or not the service-user was able to understand the material presented and therefore consent to being in the study, will be discussed in §4.3.3 whilst further consideration of the issues affecting research with adults with learning disabilities will be given in §8.3.5.

3.5.3 Recruitment to the study

Once potential service-users and their staff team had been referred to the study, they were offered an initial meeting with me, as the researcher in this project. The meeting lasted for forty-five minutes and offered an opportunity for potential participants to have the study outlined to them, to understand what participation in the study would mean for them and to ask any questions. It was made clear that their involvement in the study was voluntary and they were free to withdraw at any point without any compromise to any future services they might access. For participation in the project it was necessary to recruit both service-user *and* staff team together. If a service-user wanted to access music therapy but the staff team did not want to be part of the study, the service-user was referred to music therapy outside of this research study. Similarly if the staff team wanted to take part in a monthly staff group but the service-user they support did not want to have music therapy, the staff team was referred back to the multidisciplinary team for reallocation. Figure 3.1 shows the research protocol flowchart of the participants' journey through the study.

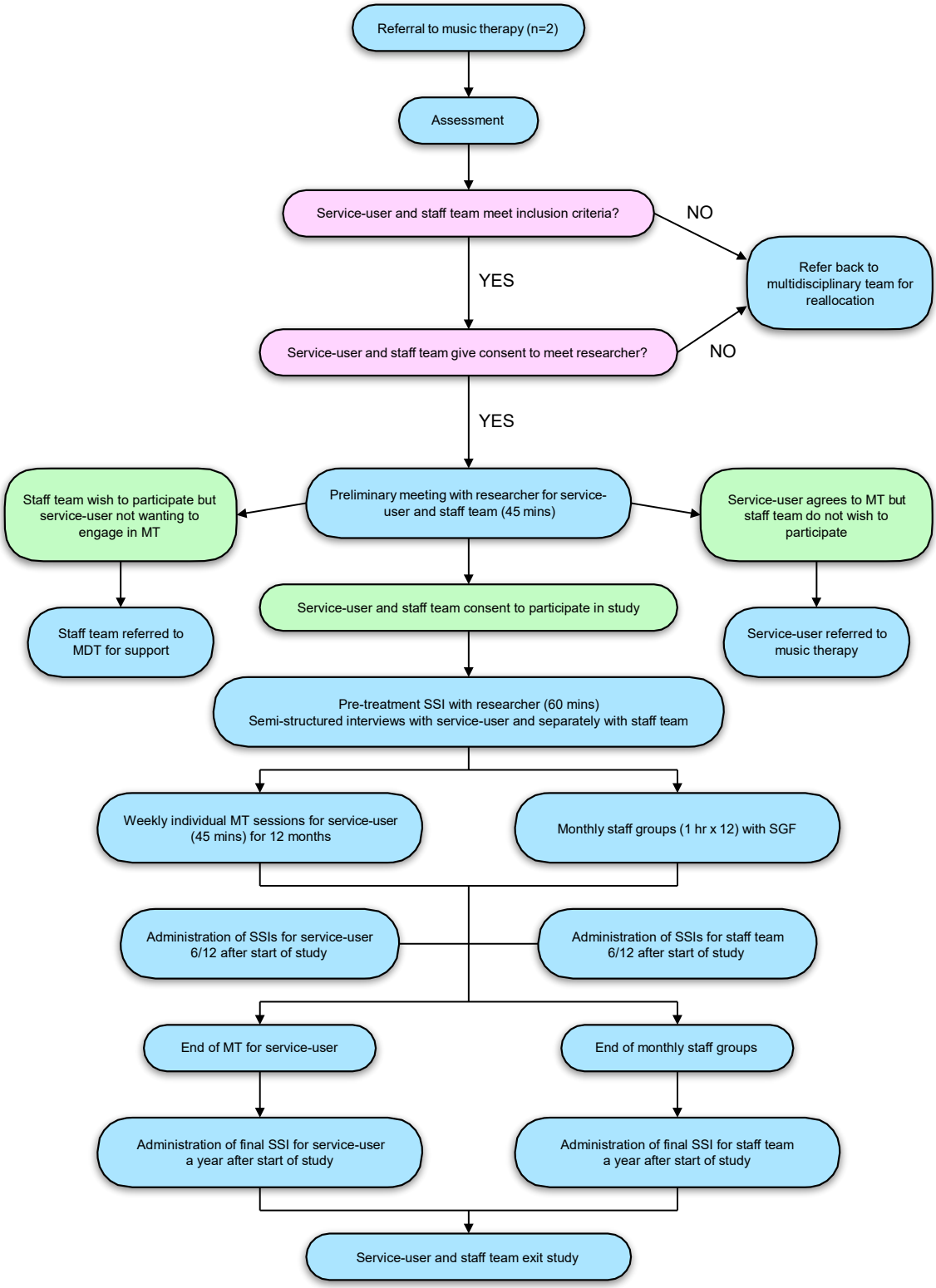


Fig. 3.1: Research protocol flowchart

3.5.4 Informed consent

When this project was first submitted to IRAS for full ethical approval, the panel raised a concern about how I could ensure that potential participants with learning disabilities were able to consent to being involved in the project and could fully understand what their involvement would mean. I had already produced participant information sheets in collaboration with speech therapy colleagues who helped me to design appropriate widgit symbols to illustrate the text, but the panel asked me to consider how I would know that potential participants had understood the information and how I intended to present the information in a way that was meaningful. (The design of the widgit symbols will be discussed in §4.3.1.)

3.5.5 Trialling the participant information sheets

The inclusion criteria for this study is that service-users would have a mild to moderate learning disability. If we refer back to §2.5.1, categorisation of learning disabilities, we can see that people with a mild learning disability have an IQ of between 50 and 70. People with a mild learning disability are usually able to hold a conversation, to communicate their ideas and to make their needs known; they may also be able to attend to their own basic care needs and accomplish everyday tasks with minimal support. People with a moderate learning disability may have an IQ between 35 and 50. Some language may well be available to them and a basic communication of needs will be possible.

I wanted to be able to ensure that the information on the participant information sheets could be broken down into manageable sections with regular checks to ensure that the service-user had understood the information up until that point. It was also an important aim of this research project to involve people with learning disabilities in the study design as far as possible. Following consultation with colleagues, I decided to trial the participant information sheets with widgit symbols with some service-users and their carers who were not going to be invited to be part of the study owing to not meeting the inclusion criteria for self-harming. Part of my role within the MDT, aside from being a

music therapist, included being a link worker to a group home within the geographical area that our team covers. The role of the link worker involves attending some of the staff meetings, getting to know the service-users that live there and acting as a link between the group home and the MDT. I approached the manager of my link house to see whether it would be possible to trial the participation sheets with three of the service-users and three members of staff.

3.5.6 Service-user involvement in the study design

It was identified that the three service-users who were invited to comment upon, and ultimately help to shape the study design, were able to understand that they were not being invited to participate in the research study but were being invited to contribute their ideas about the comprehensibility of the participation information process. Their views were also sought about the SSI questions in terms of whether the questions were clearly understandable.

I met with each service-user and member of staff twice. Initially, I read through the two participation information sheets to both the service-user and the member of staff. The first sheet outlines the study in very broad terms and asks if the service-user would like to find out more; if so, the second participant information sheet, with more detailed information is introduced. The process was repeated with the SSI topic areas. I left copies of the two participant information sheets and the SSI topic areas with the service-users and returned a week later.

All three service-users stated that they felt more confident going through the consent gaining process with a member of staff that knows them well being present. All agreed that they would feel more confident to express not understanding something than they would if a familiar member of staff was not present. In respect of the SSI topic areas, all three service-users said that they thought it would be easier to think about the topic areas with someone who was familiar to them, rather than a stranger, given how hard it might be to think about self-harming or other challenging behaviours. Two of the three service-users suggested that I read each sentence on the information sheet, point to and

describe the accompanying widgit symbol and check that the service-user understood the sentence, before continuing. There was much enthusiasm for the widgit symbols and they were mostly considered helpful in terms of facilitating greater understanding of the text. All three service-users experienced difficulty with how timescales were expressed using the widgit symbols: relatively small timescales, such as those that could be represented by a clock face or on a calendar that covered a seven-day period were fine, but the six-month time periods between the SSIs were harder to represent and there was no pre-existing widgit symbol to show this. We explored ideas of how this might be made clearer and settled on the idea of using the concept of different seasons to demonstrate a bigger interval of time. Following further collaboration with speech and language therapy colleagues, we designed a purpose-built widgit symbol based on the seasons that showed a beach scene and a snowman. I took this back to show the service-users and staff and all agreed that this felt much easier to understand. Section 4.3.1 shows these symbols.

3.5.7 Resubmission to ethics

I returned to the REC panel in July 2015 following the trialling of the participation information sheets with service-users and staff. Following a detailed description of the feedback I had received from service-users and staff about the reading of the information and the clarity of the widgit symbols relating to larger periods of time, I was able to present the ideas agreed with the service-users and staff for making the information easier to digest. My intention was to read each sentence to potential participants, indicate the corresponding widgit symbol and seek clarification that they had understood before moving on to the next statement. I was also able to show the panel the widgit symbols that had been chosen to represent a greater span of time, shown here in §4.3.1. The panel accepted these changes and the project was granted full ethical approval in July 2015. Copies of the IRAS form and the participant information sheets and consent forms with widgit symbols can be found in Appendix A and Appendix B respectively.

3.6 Weekly music therapy for the service-user

Following the semi-structured interview, the service-user began individual weekly music therapy sessions with me. Sessions were held either at the team base or a community location, e.g. a day centre within the service-user's geographical location. The purpose of the music therapy sessions was to offer a confidential space in which to reflect upon and try to understand the feelings that led to the service-user deliberately harming him/herself. As §2.8 discussed in greater depth, self-harm is complicated and the reasons for it, both conscious and unconscious, may not be immediately discernible. Music therapy offers a safe space and a trusting therapeutic alliance in which feelings and motivations can be explored. The service-users in this study were invited to think about the role that self-harm fulfils for them: for example, whether they received a particular response from care staff when they deliberately injured themselves. Other considerations included the ways in which self-harm might have become part of a lifestyle that kept the service-user in the mind of the staff team. For both service-users in this study, their self-harming frequently necessitated medical intervention from an external agency, e.g. a GP surgery, minor injuries unit or A&E. I was interested in the ways in which the framework around the act of self-harm, for example GP visits, trips to A&E and wound care, contributed to maintaining the self-harming. In other words, without self-harming, was the fantasy that the service-user might be less interesting to the staff and receive less interaction? Did self-harm provide the service-user with a narrative and a lifestyle that, in a very complicated way, felt too difficult to relinquish? The music therapy sessions for the service-users in this study will be discussed more fully in §4.7.

3.7 Clinical interventions: psychoanalytic concepts

This section will describe some of the psychoanalytic frameworks that inform my clinical work. My understanding of what takes place within the therapeutic encounter is influenced by a number of psychoanalytic concepts that underpin my clinical practice and therefore influence how I practice music therapy. These include attachment theory, transference and countertransference, group analysis and the work of Bowlby, (1973;

1979 and 1988), Bion (1959), Stern (1985), Winnicott (1953; 1956; 1965 and 1971) and Foulkes (1964; 1975 and 1957). These models of psychoanalysis provided me with a framework in which to consider the events that took place within the music therapy arena and to ascribe meaning to the service-users' words and music.

3.7.1 Attachment theory

Attachment theory was developed by John Bowlby (1907–1990) and later Mary Ainsworth (Ainsworth and Bowlby, 1965). Bowlby was interested in the effects of separation between children and their caregivers and the implications such separations might have for the child's future relationship patterns. Bowlby himself was raised by a nanny and spent long periods of time separated from both parents. In keeping with prevailing social norms of upper middle-class families of the time, Bowlby spent about an hour a day with his mother, whilst his father went away to work. Parental conventions of the day suggested that a child might be spoiled or over-indulged if showed too much love or affection. Following undergraduate studies at Cambridge, Bowlby worked at a school for disadvantaged children where he encountered two young people who made a particular impact on him: one was an isolated teenager with no stable parental figure in his life; the other was a younger child (around 7–8 years old) who followed Bowlby everywhere and became known as his shadow. These children first aroused Bowlby's curiosity and led to him developing his ideas about attachment. Through his work with children, Bowlby developed his ideas about the correlation between early family experiences and a child's emotional well-being. He later met Mary Ainsworth who had been developing her own ideas about security theory, the idea that children need to develop a dependence on their parents before being able to successfully separate from them later on. Together they developed their theory about attachment and categorised these into four attachment patterns:

3.7.1.1 Secure attachment

Children who are securely attached are more likely to experience other people as helpful and supportive and to think of themselves as acceptable and worthy of respect.

Securely attached children are likely to be curious about other people, to engage and play confidently with others and to show greater resilience. As adults they are more likely to have a successful partnership which allows them to feel emotionally attached to their partner without the need to always be with them. They have internalised a healthy working model that allows them to feel kept in mind without needing to be physically together all the time.

3.7.1.2 Anxious avoidant attachment

Children with an anxious avoidant attachment pattern find it difficult to manage stressful situations effectively. They may try to manage this by distancing themselves from others and developing a self-reliance. Aggressive behaviour, which might include bullying and lying, is more prevalent in children with an anxious avoidant attachment pattern. They are also less likely to ask for help or to actively engage with others, which may make establishing positive relationships with other people more difficult. As adults, those with an anxious avoidant attachment may prefer to live a life that has little need of human connection, believing that they do not need a relationship in order to thrive. They are usually self-reliant and independent and have the capacity to be emotionally closed off at times of stress.

3.7.1.3 Anxious resistant attachment

This could be described as the opposite end of the spectrum to the anxious avoidant attachment pattern. Children who are anxiously resistant tend to stay very close to their primary carer and may cling to this person for fear of separation. They may lack self-confidence and have limited relationships with their peer group. As adults, people with anxious resistant attachment patterns may depend upon their partner's constant presence to keep them feeling securely attached and may feel desperate for constant reassurances of love and affection. Conversely, their longing for reassurance may, in fact, lead them to behave in ways that might push people away. People with an anxious resistant attachment pattern may easily be upset by small grievances, or may be jealous, clingy and overbearing in their relationships.

3.7.1.4 Disorganised attachment (or fearful avoidant attachment)

Children with a disorganised attachment pattern experience others as a threat rather than as a source of potential support. They are not well-equipped to deal with separation distress and as such, may oscillate between withdrawing, disruptive and aggressive behaviour. As adults, their attachment style can be described as ambivalent rather than withdrawing, and people with a disorganised attachment may try to avoid their emotions for fear of being overwhelmed by them. They may be unpredictable and display mood swings and sudden aggressive outbursts. People with this kind of attachment pattern may simultaneously seek a close, loving relationship, whilst fearing the intimacy that such a relationship might bring.

3.7.1.5 Implications of early attachment experience on adult relationships

Therapists are usually interested in attachments and the ways in which our earliest experiences have a bearing on our capacity to make and maintain healthy relationships in adulthood. For the infant, attachment is crucial to survival: the primary care-giver is the source of all physical and emotional sustenance and the infant is completely dependent on them. Infants have a number of ways to ensure that their needs are met and thus their survival is assured. Soltis, referring to Bowlby's work on attachment theory, suggests that a signalling system such as an infant crying was 'adaptive during human evolutionary history because maintaining proximity to mothers protected infants from predators' (Soltis, 2004, p. 447). Swain, Mayes and Leckman state that a baby's cry plays 'a critical role in the formation of attachments with caregivers' (Swain, Mayes and Leckman, 2004, p. 472). When a good attachment is developing, babies quickly learn that crying brings their primary caregiver and that they will know what the infant needs and be able to provide it. Ainsworth, Bell and Stayton describe how the development of a healthy attachment depends upon the primary caregiver's 'ability to perceive and interpret accurately the signals and communications in the infant's behavior and, given this understanding, to respond to them appropriately and promptly' (Ainsworth, Bell and Stayton, 1974, p. 127).

Through receiving this response, the baby learns to trust in the reliability and consistency of the caregiver. In cases of a poor attachment something goes awry in this process. It may be that due to various factors, including disability, the baby may not be able to alert its caregiver to its needs. The author Kenzaburo Ōe, in his novel *The Silent Cry,* writes of a father contemplating his disabled son:

> 'The baby gazed up at me as ever with wide-open eyes but whether he was hungry or thirsty or felt some other discomfort I couldn't tell. He lay with eyes open and expressionless, like a marine plant in the water of the dusk, simply and placidly existing. He demanded nothing, expressed absolutely no emotion. He didn't even cry.'
>
> (Ōe, 1967, p. 11)

If factors, including a lack of crying, impede the primary caregiver from being able to recognise or respond to their infant's needs, the infant may internalise an inner working model that adults cannot be relied upon to ensure their safety and survival. Such early attachment experiences can shape our relationships and the way we go on to experience the world in adulthood. As Simpson et al. suggest:

> '[our] personal history of receiving care and support from attachment figures across the life span shapes the goals, working models and coping strategies that one uses when emotion-eliciting stimuli or events occur in relationship contexts.'
>
> (Simpson et al., 2007, p. 355)

For adults with learning disabilities, particularly those in their middle years, their earliest attachments may have been interrupted by their placement, at a young age, into a long-stay institution, as was common in the 1960s and 1970s. Life within such an institution afforded few opportunities for meaningful, sustained relationships. Staff turnover was often high, meaning that staff came and went quickly and with possibly little warning. Within such a context it is possible to see how people might quickly become rather isolated or develop complex defences in order to deal with institutional life.

3.7.2 Transference and countertransference

'Transference' and 'countertransference' are central tenets in psychoanalytic thinking. Freud first described the unconscious processes of transference and countertransference around 1901 and wrote this definition of transference:

> 'Transferences are new editions or facsimiles of the impulses and phantasies which are aroused and made conscious during the process of analysis but they have this peculiarity which is characteristic of their species, that they replace some earlier person by the person of the physician. To put it another way: a whole series of psychological experiences are revived, not as belonging to the past, but as applying to the person of the physician at the present moment.'
>
> (Freud, 1901, p. 157)

If transference describes the attribution of feelings towards figures in the patient's past on to the therapist, countertransference can be described as the feelings that the patient evokes in the therapist in the here and now, or, as Anthony Storr describes it, 'the therapist's emotional attitude towards his patient' (Storr, 1979, p. 69).

Countertransference describes a psychoanalytic concept that takes place within the therapeutic encounter whereby the complex interplay of feelings that the patient and therapist evoke in each other can be thought about and used in potentially helpful ways to the patient. The therapist may become aware of feeling, for example, very irritated or very tired during a therapy session, for reasons that have no obvious external explanation outside of the therapeutic encounter. Recognising these feelings as belonging to the countertransference allows the therapist to use their understanding of this to explore the origins of these feelings with the patient.

3.7.2.1 Musical countertransference

Similarly, as music therapists, we are making musical responses to our patients based on how we understand our patient's music and how it makes us feel. Casement turns to a musical analogy when describing countertransference:

> ‘The greater freedom therapists have to resonate to the unfamiliar keys or dissonant harmonies of others, the more it will enhance their receptivity to these unconsciously interactive cues that are often central to an understanding of patients.’
>
> (Casement, 1985, p. 95)

We use our experience of our patients’ music to inform and guide our musical responses and offer containment of the complex and often unmanageable feelings of our patients. Streeter, in 1999, offered a definition of musical transference and countertransference in which she suggested that:

> ‘Creating music in music therapy allows one to reconnect with the child within and, very often, the pain which that re-engenders — the re-experiencing of the obstacles to self-expression through play.’
>
> (Streeter, 1999, p. 86)

Streeter argues that understanding music in this way invites some particular questions about what we, as music therapists, might play in response to our patients’ music and why we might make the particular musical responses that we do. She is interested in the ways in which what happens within the musical encounter reflects what happens within the verbal arena of a session. Streeter suggests that we are accustomed to listening to ‘unfamiliar keys and dissonant harmonies’ (Streeter, 1999, p. 95) and that part of a music therapist’s musical countertransference response is in the ways in which they ‘play with, construct alongside and sound out our responses to their music’ (Streeter, 1999, p. 95). I will refer to and illustrate this idea further in §5.4.3.1 and §5.4.3.2.

Therapists regularly refer to the concepts of ‘containment’ and ‘holding’ and this next section will offer a description of these terms and their relevance to music therapy practice.

3.7.3 Bion and the concept of containment

Therapists often use the term ‘containment’ to describe a response to an aspect of the therapeutic process in which patients project their unmanageable feelings on to the therapist. He or she, by listening, absorbing and reflecting these feelings, can offer

them back in a more digestible form to the patient, who can then re-experience them as more tolerable because they have first been tolerated by the therapist. In Bion's words:

> 'When the patient strove to rid himself of fears of death which were felt to be too powerful for his personality to contain he split off his fears and put them into me, the idea apparently being that if they were allowed to repose there long enough they would undergo modification by my psyche and could then be safely reintrojected.'
>
> (Bion, 1959, in Bott Spillius (ed.), 1987, p. 96)

The 'modification' that Bion refers to suggests to me possible parallels with ideas of musical transformations, a concept with which music therapists will be familiar. As music therapists we listen to our patient's music and respond with our own, using this musical dialogue to transform, develop, extemporise and provide a context for the patient's music.

Bion describes the earliest experience of containment through the experiences of the infant and its mother. The infant projects into the mother feelings that are intolerable: these might be frightening, upsetting or painful in some other way. The mother receives these feelings, feels them herself but, crucially, is able to survive them and, as a result of this, is then able to return the feeling to the infant in a contained form which the child can then accept and integrate into his or her own emotional experience. I am interested in the ways in which this might mirror a musical interaction and in particular how a patient might use the music as a vehicle for projecting powerful, intolerable feelings into the therapist. He or she then receives this music, responds and offers the music back to the patient in a way that they can hear, experience and tolerate. There will be an example of this in the case study in §5.4.3.1 and §5.4.3.2.

3.7.4 Winnicott's concept of holding

Describing the concept of 'holding' in 1953, Winnicott explains that the function of the 'good-enough' mother is to manage her infant's distress by providing comfort and safety, shielding her child as much as possible from the impact of stressful emotions. An important aspect of the 'good-enough' mother is that she can make careful and

timely adjustments that allow her infant to experience moments of frustration, as he or she becomes developmentally ready to manage this without becoming psychically overwhelmed:

> 'The good-enough mother…starts off with an almost complete adaptation to her infant's needs, and as time proceeds she adapts less and less completely, gradually, according to the infant's growing ability to deal with her failure.'
>
> (Winnicott, 1971, p. 14)

Casement's definition suggests that holding, as well as being something that a mother offers an infant, is also something that one adult can offer to another, hence allowing its possibilities to be transferred to the therapeutic encounter:

> 'What is needed is a form of holding, such as a mother gives to her distressed child. There are various ways in which one adult can offer to another this holding (or containment). And it can be crucial for a patient to be thus held in order to recover, or to discover maybe for the first time, a capacity for managing life and life's difficulties without continued avoidance or suppression.'
>
> (Casement, 1985, p. 133)

I think that the music therapy encounter, with its opportunities for shared music making, particularly lends itself to this concept. Whilst we might be readily familiar with the idea of music to soothe and relax, within music therapy there exist opportunities for the patient to experience being held in the music by the therapist who is able to provide a musical framework in which the patient can feel safe enough to experience some of the more unmanageable aspects of their inner world. Again, this psychoanalytic concept will be illustrated in the case study chapter, §5.4.4. Staying with the maternal relationship, this next section will discuss Daniel Stern's concept of affect attunement and the particular resonances that this holds for music therapists.

3.7.5 Daniel Stern and affect attunement

Whilst observing mothers with their babies, Stern noticed an inherent reaction of the mothers towards their babies: the mothers appeared to sense and react to their infants' movements and behaviours with what he described as an 'empathic

responsiveness' (Stern, 1985, p. 138). Interaffectivity (Stern, 1985, p. 132), the concept of mirroring an element of the baby's gesture and making an empathic response back to the infant, allows for the idea that the caregiver is able to perceive something of their infant's internal experience and respond to it before the baby develops the capacity to use language to describe experience. These responses, which Stern describes as 'affect attunement' (Stern, 1985, p. 140) responses are more than simply an imitation of the infant's behaviour. Attunement behaviours indicate an understanding by the caregiver of the meaning and internal experience that gave rise to the baby's behaviour and allow for the idea that feelings can be shared and understood in a state of mutual affect. Stern describes three components to this exchange of intersubjective affect which I have summarised below:

- the caregiver is able to recognise their infant's affect through their behaviours
- the caregiver responds with behaviour that matches the affect of their baby's behaviours although the modality of this behaviour might be different
- the infant is able to recognise the caregiver's response as corresponding to its own original behaviour

Affect attunement therefore allows for the possibility that affect states and internal experience are sharable with another. Whereas a simple imitation only shows that the caregiver understood what the infant did, an affect attunement response allows for the notion that the idea and feeling behind the gesture have also been understood. Rather than imitating the behaviour back to the infant, the caregiver matches the behaviour on one of the following continuums: timing, rhythm, intensity and the overall shape of the behaviour. In this way an infant's vocalisation might be matched by a shimmying body movement: a different modality, but a sharing of the affective state.

The idea of affect attunement may have a particular resonance for music therapists, dwelling as we do in the arenas of musical attunements, misattunements, connections and relatedness. This concept within music therapy will also be illustrated within the case study in §5.4.4.1 and §5.4.6.

3.7.6 S H Foulkes and the Group Analytic Matrix (GAM)

Complex and unconscious processes are at work when a group meets without a precise agenda and in a largely unstructured way. Although the Juniper staff group (introduced in §5.3) were meeting for a specific purpose, i.e. to think about their experience of supporting somebody with a learning disability that self-harms, each of the twelve monthly staff groups, facilitated by my colleague, was unstructured; the staff team was encouraged to use the group in the ways that were most important and meaningful to them. In this sense, my colleague acted as a group facilitator (hence the term staff group facilitator or SGF), rather than a leader or director, guiding the group according to the direction that they themselves determined. Our understanding of group practice is informed by the work of S H Foulkes and his theories of group analysis. Working in England after the Second World War, Foulkes developed an interest in the unconscious processes and motivations that drove the dynamics in the group analytic therapy groups that he was working with. He formulated his ideas about these unconscious processes and developed the concept of the Group Analytic Matrix (GAM) (Foulkes and Anthony, 1957, p. 258). The GAM recognises the lack of a single physical body but instead acknowledges the idea of the group-as-a-whole. Interestingly Foulkes uses the metaphor of an orchestra to illustrate this:

> 'If we hear an orchestra playing a piece of music, all the individual noises are produced each on one particular individual instrument; yet what we hear is the orchestra playing music, the conductor's interpretation etc. We do not even in terms of pure sound hear a simple summary, a summation of all the individual waves which reach our ears, but these are modified significantly, being part and parcel of a total sound. In truth what we hear is the orchestra. In the same way mental processes going on in a group under observation reach us in the first place as a concerted whole… With this insight we have arrived at one of the basic concepts in group psychotherapy…namely what we experience in the first place is the *group as a whole.'*
>
> (Foulkes and Anthony, 1957, p. 26)

He gives the following definitions of the matrix:

> 'the network of all individual mental processes, the psychological medium in which they meet communicate and interact.'
>
> (Foulkes and Anthony, 1957, p. 26)

‘In this group network all processes take place, and in it they can be defined with regard to their meaning, their extension in time and space, and their intensity.’

(Foulkes and Anthony, 1957, p. 258)

‘The group matrix can be regarded as the operational basis of all mental processes in the group.’

(Foulkes and Anthony, 1957, p. 258)

In diagrammatic form ‘the network of all individual mental processes’ (Foulkes and Anthony, 1957, p. 26) might look something like Figure 3.2.

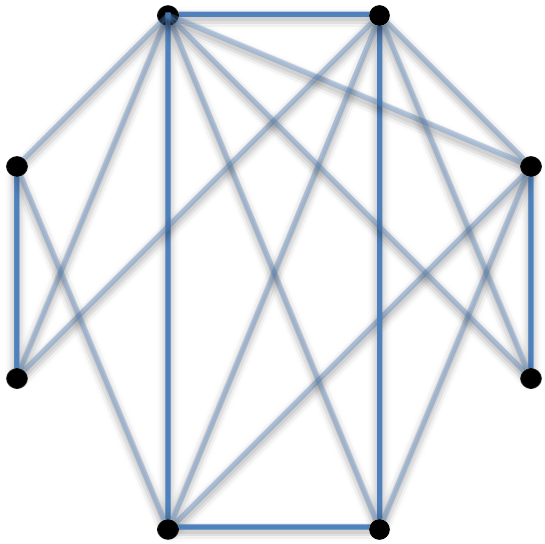


Fig. 3.2: Representation of a group matrix

The matrix can therefore be thought of as an arena in which relationships, events and interactions exist and play out between the members of the group.

3.7.7 Splitting

Another psychoanalytic concept which informed some of my thinking about the processes in the staff groups is ‘splitting’. First identified by Freud, splitting is a mental process in which two distinctive and contradictory versions of reality can co-exist. Klein (1946) believed that splitting involved the division of the ego between the instincts of love and hate. She described the ways in which a child needs to retain ‘good’ feelings and project ‘bad’ feelings into another external object. Newborn infants,

trying to make sense of an entirely new and unfamiliar environment, first attempt to understand their experiences by organising them into 'good' and 'bad': 'good' experiences feel gratifying and those that cause pain or frustration are experienced as 'bad'. The infant is attempting to divide up a tangled mass of experience and sensation so that it can be both predictable and better understood. Splitting allows us to make helpful distinctions and ascribe meaning to experiences. It can become a less helpful defence mechanism when the opposite happens: meaning is removed by separating parts of a whole that belong together. Unacceptable feelings that cannot be tolerated or integrated become split off and rejected, unavailable for thought. This will be discussed within the context of participant B's staff team in §5.5.4 and expanded upon further in the context of the staff groups in the final synthesis in §6.8.

3.7.8 Projective identification

Projective identification was first described by Melanie Klein in 1946. It describes the process whereby unconscious parts of the self are defensively projected into another person to evoke, in them, the feelings or thoughts originally belonging to the person projecting them. R D Laing says that:

> 'The one person does not use the other merely as a hook to hang projections on. He/she strives to find in the other, or to induce the other to become, the very embodiment of projection.'
> (Laing, 1969, p. 93)

In terms of this research study, projective identification informed my thinking, particularly in respect of the SSIs carried out with the staff teams. The phenomenon of projective identification seemed, at times, to be very active in the staff teams and examples of this will be given in §6.8.1.

3.8 Monthly groups for the staff team

After the administration of the first SSI, the staff teams began to meet once a month for an hour-long group facilitated by the SGFs. Since service-users and their staff teams were recruited to the study together, the groups for the staff teams focused specifically

on their experiences of supporting the service-user that they had joined the study with. Although both staff teams were involved in supporting other service-users, it was beyond the scope of this study to consider the service-users that were outside of the study. The SGFs managed this boundary within the groups and guided the discussions to focus only on the service-users who were involved in the study. Opportunities did exist to consider the wider dynamics that were in play between the staff teams and their respective service-users. 'Dynamics', or 'group dynamics', refers to the unconscious psychological processes and behaviours that occur within a social group. For these staff groups, brought together in their collective role of supporting their service-user, there was the chance to examine how they felt about their service-user's self-harming, how they responded to it and to think about the unconscious rivalries, envious attacks and splitting that was a part of their experience. Providing a space where some of these unconscious feelings could be examined and carefully thought about potentially allowed for new ways of understanding each other to emerge. It also allowed the staff to think about some of their more ambivalent feelings towards their service-users and their self-harming. The staff groups will be discussed more fully in the context of the case studies in Chapter 5 (§5.3, §5.5, §5.5.4, §5.9, §5.9.2, §5.9.3 and §5.9.4).

3.9 Statistical considerations and implications

3.9.1 Sample size

The single-case, qualitative study design of this research project lends itself to a small sample size where rich and detailed data is extracted from semi-structured interviews. Smith, Flowers and Larkin argue that because, in phenomenological research, 'the issue is quality, not quantity…IPA studies usually benefit from a concentrated focus on a small number of studies' (Smith, Flowers and Larkin, 2009, p. 51). My intention in this study has been to elicit authentic and detailed data that allows the experiences and voices of the service-users and staff teams to be at the heart of this work. I felt that this was best achieved by the detailed analysis of two case studies.

3.10 Confidentiality and data protection considerations

Care was taken to ensure that sharing of personally identifiable information adhered to the Caldicott guidelines which state that the sharing of personal data is strictly on a need-to-know basis. Each service-user and staff team was allocated a code and any personally identifiable information was removed from the transcripts of the SSIs to ensure that confidentiality was maintained.

Any written data was encoded and stored in a locked facility to which only the researcher had access. All electronic data was encrypted and securely stored on a password-protected external hard drive which was also stored in a locked facility. Written and electronic data were only accessible to the researcher.

The management of all data adhered to the United Kingdom Data Protection Act of 1998.

3.11 Risk management

Risk management strategies were considered for the purposes of ensuring the safety of service-users, staff teams, researcher and research assistants. These are outlined in §A22/23 and §A26 of the IRAS form which can be found in Appendix A.

Chapter 4: Method

This chapter will begin with a reminder of the research questions, focusing on the components of the study which together provide and contribute to the generation and analysis of the data. Following this, there will be a description of the method of recruitment, meeting potential participants, gaining their consent and entering the study. I will describe the process for devising the participation information sheets and the use of widgit symbols to enhance the text. The method for designing and administering the SSIs will be described and procedures for the data collection and analysis will also be discussed. Music therapy clinical methods will also be described here. Methods for conducting both the music therapy sessions and the staff groups are also considered.

4.1 Context and research questions

The research questions that this study seeks to address were stated in §3.1 with further clarification in §3.1.1. These research questions had initially been formulated through a rise in referrals to our MDT of people with learning disabilities and a chronic history of self-harm and then refined by a consideration of the literature. At the end of Chapter 1, I discussed an informal study that took place in our service which showed a positive correlation between monthly staff groups alongside weekly music therapy for the service-user and a reduction in self-harm. Changes in the staff's understanding about self-harm and differences in the ways they were able to respond to it were also observed.

4.1.1 The components of the research project

This study has three components to it, which together provided and contributed to the analysis of the data generated in this project.

- **SSIs:** the SSIs for both the service-users and the staff teams were the main source of the data that were analysed within IPA. All interviews were recorded and transcribed verbatim in preparation for analysis.

- **Music therapy sessions:** the music therapy sessions for the service-users were recorded and listened to. Through these weekly sessions any changes, both verbally and musically, were observed and this contributed to the analysis of the data generated through the SSIs.

- **Monthly staff groups:** the monthly staff groups for the care staff were also recorded and listened to. Changes observed through how the staff team talked about understanding and responding to self-harm also supported the analysis of the SSIs.

The ways in which change was measured throughout this study was discussed more fully in §3.1.1.

4.2 Setting up the research project

4.2.1 Recruitment

Once full ethical approval had been received, I was able to begin recruiting participants to the study. As discussed in §3.5.3, I was recruiting service-users with their care staff team, as this research investigates interventions with both the service-user and the care staff team simultaneously. This was illustrated by the referral pathway shown in Figure 3.1. Referrals were sourced from five MDTs that make up the local NHS Trust. The five MDTs cover a mixture of city and rural locations. Each team is responsible for providing health and social care support within a defined geographical area. I visited each team to give a short presentation of my research project at the team's weekly practice meeting. I took information sheets about the study, copies of participation sheets and consent forms. We discussed how the teams could refer to the study and how I would maintain contact with the team regarding anyone who was accepted into the research project. Any clinician from the multi-disciplinary teams was welcome to

contact me via phone or e-mail to refer a service-user and their staff team to the study. The referrals generated from each of the five teams are shown in Figure 4.1 in §4.2.3 below.

4.2.2 Maintaining links with the MDT

As discussed in §3.4.3, my role in this research study crosses the two domains of clinician and researcher. In my role as clinician I work as a music therapist on a part-time basis across two of the five geographical teams that make up the NHS Trust. Therefore, in two of the teams that I presented my study proposal to, I already held a clinical role, part of which included attending weekly practice meetings. The remaining three teams were less well known to me, although each contained one or two of my arts therapy colleagues. Important questions arose about how best I could maintain links with and offer appropriate feedback to those MDTs in which I did not have a clinical role and therefore did not attend weekly practice meetings. It was agreed that if a referral came from a team in which I had no clinical role, I would maintain contact with the person who had made the referral; any feedback or concerns that were deemed necessary for the team to be aware of would be communicated via this person.

4.2.3 Referral trends

On receipt of a referral, a visit to the service-user and staff team was arranged along with the person who had made the referral.

Although six service-users and their care staff teams were referred into this study, only two met the full criteria for inclusion. Figure 4.1 shows the number of referrals made from each of the five teams.

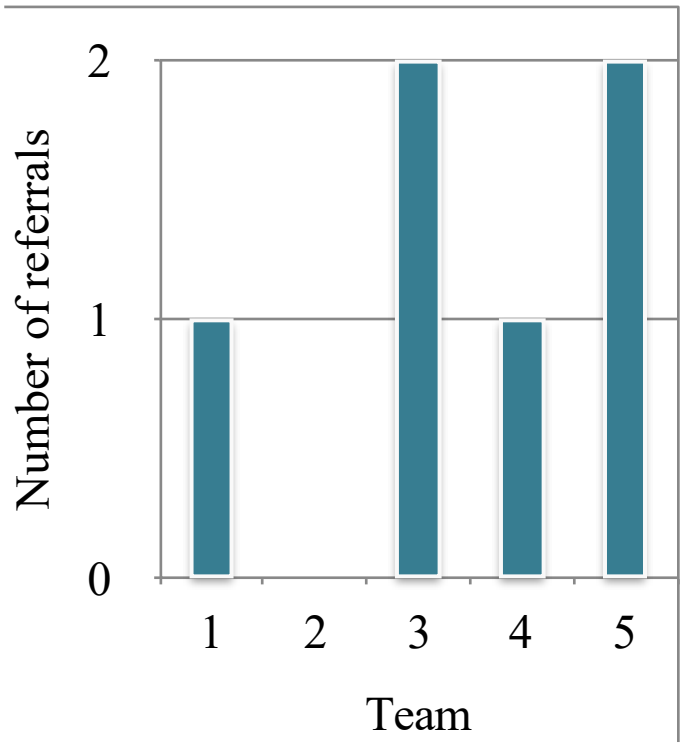


Fig. 4.1: Histogram of referrals to the study

4.2.4 Referral numbers

Referral numbers were lower than I had been anticipating given the national picture of self-harming rates discussed in §2.6. Prevalence estimates of self-harm within the adult learning disability population vary widely depending on the method used for measuring and the definition of self-harm adopted. The most recent study looking at prevalence rates (Summers et al., 2017) suggests that prevalence is much greater, at 50%, in adults with autistic spectrum disorders (ASD) than in adults with learning disabilities alone, where the percentage is 4.9%. The investigators did, however, note a 33% prevalence rate in people with severe learning disabilities. Although the study identified the risk factors as including having ASD and having a greater severity of learning disability, the sample size did not allow for further investigation into how the risk factors contributed towards the prevalence of self-harm. When I outlined this research study for the purpose of recruitment to the five MDTs, it became clear that, whilst each of the teams knew of between five and ten service-users with a chronic history of self-harm, a

significant number of these lived within the family home and therefore had a different means of support that did not necessitate a care staff team in the traditional sense. This was the most significant factor affecting why some potential referrals to the study did not meet the inclusion criteria. Other factors included a potential participant who fulfilled the criteria for inclusion at the time of referral but had been offered a house move to more independent accommodation and a service-user for whom self-harm had stopped being a concern.

4.2.5 Initial meetings with potential participants

Table 4.1 shows the demographic information of the participants referred to the study and the reasons why the inclusion criteria were not met, if applicable. Participants are listed in the order in which they were referred.

Participant	Referring team	Reason for referral	Accommodation	Fulfils criteria?	Outcome
A	Team 1	Self-harm/mental health issues	Group home supported by staff team but hoping to move into more independent accommodation	No – service-user moved	Service-user moved out of county so was not eligible for inclusion in the study
B	Team 3	Bereavement/ chronic history of self-harm	Group home supported by staff team	Yes	Service-user and staff team joined the study
C	Team 3	Intermittent episodes of self-harm, particularly when there was a lack of day care provision	Group home supported by staff team	No – when I visited service-user and staff team, both reported that self-harm was not a current concern	Service-user not engaging in self-harm at time of study
D	Team 5	Difficult family issues/chronic history of self-harm	Lived within the family home	No – due to accommodation and lack of staff team.	Service-user referred to arts therapies outside of research study
E	Team 5	Complex family situation/self-harm	Lived within the family home	No – due to accommodation and lack of staff team	Service-user referred to arts therapies outside of research study
F	Team 4	Chronic history of self-harm	Semi-supported living with staff team	Yes	Service-user and staff team joined the study

Tab. 4.1: Demographic information of participants referred to the study

Of the six referrals to the study, I met with four potential participants and their staff teams to outline the study.

4.2.5.1 Participants who did not fulfil the criteria

Participant A was referred to the study by his community nurse because of a long history of self-harm and suicidal ideation. I met with him and his staff team to outline the study and present the participation information materials. Although both he and his staff team were keen to join the study, a house move was imminent and the service-user moved out of county, thereby making him ineligible for participation. He was referred to the music therapist in his new team.

Participant C was referred to the study because of a history of intermittent periods of self-harm. This became more manifest at times of stress or during periods where her daytime activities stopped, such as outside of term time when day centre and college activities closed. I met with her at the group home where she lived, along with a member of the staff team. Participant C was able to give a good account of herself and felt she was in a 'good place'; her self-harming was not a current concern for her. She felt she did not want to engage in the study, nor did she require any other support. No further intervention was offered to her.

I did not meet with potential participants D and E as they were both living within the family home and did not have access to a care staff team, meaning they were ineligible for inclusion in the study. Both of these potential participants were referred to arts therapies services outside of this research.

4.2.5.2 Participants who did fulfil the criteria

I first met with participant B and his staff team in July 2016. He lived in a small group home. He was socially isolated and was bereaved of both parents. He had a long-standing and chronic history of self-harm that involved hitting his arms and legs against sharp objects, causing bruising, swelling and, on occasion, broken bones. He was supported by a staff team that knew him well and were motivated to better understand the participant's self-harm and how they could best offer him support. Both participant B and his staff team met the criteria for entry into the study. The participation

information sheets were shared with both the service-user and his staff team. All gave written consent; that of the service-user was witnessed by a member of staff and myself as researcher and the consent of each of the staff members was also witnessed by me. Participant B and his staff team entered the study in September 2016.

I met participant F and her staff team in August 2017. She lived in her own flat and had visiting daily support from a staff team who supported her with personal care, shopping, cooking, cleaning and appointments. Participant F was very socially isolated, spending much of the day in her flat watching TV, apart from the time she spent with staff. She and her staff team described her self-harming as the voluntary urination onto ulcerated, heavily bandaged legs and then poking sharp objects down her bandages to scratch the wounds. Participant F's staff team had known her for many years and expressed a wish to understand the reasons and motivations behind her self-harming. The participant information sheets were shared with participant F and her staff team and consent was given and witnessed as for participant B. Participant F and her staff team entered the study in September 2017.

4.3 Devising participant information sheets and widgit symbols

4.3.1 Widgit symbols

For the participant information sheets to be meaningful and understandable for people with learning disabilities, I consulted with speech and language therapy colleagues to devise information that contained both simple text and an accompanying widgit symbol. Widgit symbols (Widgit Online, 2019) are images made up of simple drawings and/or signs that help to represent a concept. They are often used alongside simple text to enhance meaning. There are currently over 12,000 widgit symbols available, covering a vocabulary of approximately 40,000 words. Figure 4.2 shows some examples of widgit symbols that were researched when devising the participant information sheets and consent forms for this study.

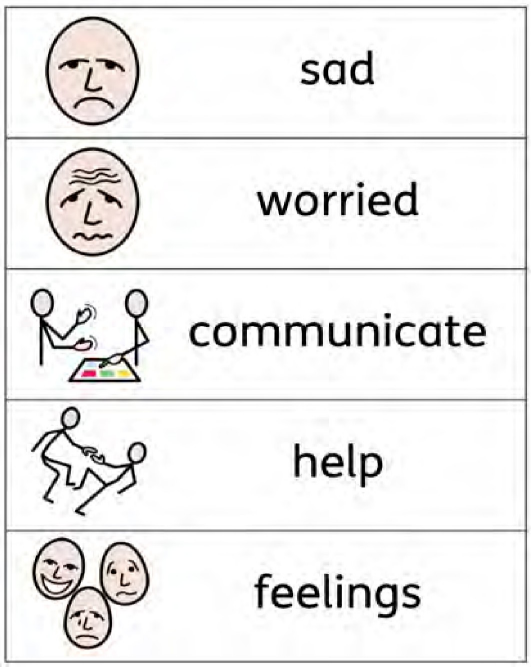
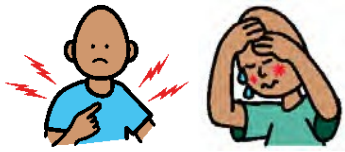
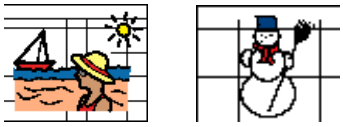


Fig. 4.2: Examples of widgit symbols

The first two widgit symbols are representative of the word they describe, but, as the text becomes more abstract, as in the last three examples, it is possible to see how the widgit symbol expresses a concept and helps to enhance the overall meaning of the text. When I first met with speech and language therapy colleagues in May 2014, we discovered that some of the concepts that I wanted to convey did not have a widgit symbol. For these participation information sheets, the most important concept for which there was currently no widgit symbol was self-harm. Along with my colleagues in the speech therapy team we researched thousands of existing widgit symbols to see how we could create a symbol that reflected the accompanying text: (people with learning disabilities) 'who hurt themselves when they feel unhappy.' The resulting symbol that we created took the essence of each part of the statement and captured each with a symbol: 'hurt themselves' and 'feel unhappy':



As discussed in §3.5.7, timescales were also difficult to capture. After initial collaboration with the service-users who were asked to assist with the study design without participating in the study, it was decided that there needed to be a way of showing that the SSIs for the service-users would take place at six-monthly intervals and it was felt that this was most easily pictorially represented by a change in the seasons. 'Each visit will be six months apart' was captured by a summer scene followed by a winter scene:



For service-users, I produced three sheets using widgit symbols alongside text. The first of these was an introduction leaflet, outlining the study very broadly, and the second was the more substantial participation information sheet with additional detailed information about what taking part in the study would involve. The final sheet is the consent form, which again has text and widgit symbols, but also has boxes to tick and a space for the service-user or their representative to sign in order to give consent to participate in the research project. These three sheets and the participant information sheet and consent form for the staff teams are reproduced in Appendices B and C.

4.3.2 Amendment to the IRAS form

When this study was first submitted for ethical approval, the REC requested further clarification about how I would ensure that prospective participants understood fully what involvement in the study would mean. I made an amendment to the IRAS form outlining more clearly how the study would be explained to potential participants. The process began by a member of any of the MDTs (the referrer) identifying a service-user and staff team that might meet the criteria for inclusion. The referrer would contact a member of the staff team by phone to see if they would be prepared to meet me and find out about the study. If so, I then contacted the staff member and arranged a time to visit to present the participant information sheets. I made four visits to potential participants.

With the exception of participant C, who declined to be part of the study based on her current improved situation and not wishing to have the study outlined to her, the three other potential participants and their staff teams were shown the initial information sheet followed by the more detailed one (see Table 4.1).

4.3.3 Presenting the participant information sheets

The information sheet was shown to the service-user and the staff member at the initial meeting. These initial meetings at which a member of the staff team, the service-user and myself were present, lasted for 45 minutes and took place in the service-user's home. The participant information sheets contained both text and widgit symbols. I read out each sentence and indicated the accompanying widgit symbol. After each sentence I checked with the service-user that they had understood. This was then validated against the staff member's sense of whether the information had been understood by the service-user. The rationale for having the staff member present was their knowledge of the service-user. I wanted to protect against a service-user feeling unable to say if they did not understand and the presence of somebody who had a relationship with them would hopefully provide reassurance. If the service-user indicated that they had not understood, either verbally or by shaking their head, and if this was validated by the staff member's impression, then it would be understood that the service-user did not have capacity to consent, based on an understanding of what the study involved, and therefore did not fulfil the criteria to participate in the study. If the service-user was considered to have understood the initial information sheet and they and the staff member wished to find out further details about participating in the study, the more detailed participant information sheet was offered to the service user. The information sheet for the staff was given to the staff member for discussion with their manager and staff team. The potential participants then had the option to look at the forms in their own time and then have another 45-minute follow-up visit from me a week later to discuss any thoughts or questions that might have arisen. I could also go through the participant information sheets at the initial meeting if this was preferred; indeed, of the three potential participants that requested further information, all were happy for me to discuss the participant information sheets at the initial meeting and did

not want time to think about taking part in the study. The staff members who were present at these initial meetings shared the information with the remainder of their staff teams during the following week, to ascertain the viability of a core staff team that was willing to participate. Once a viable staff team had been recruited to the study, within two weeks of the initial meeting, I returned to meet with the whole staff team together to discuss the study and to clarify that each staff member fully understood what participation in the study would involve. At this point consent forms were signed by each of the staff members and a separate consent form with accompanying widgit symbols was signed by the service-user. The signatures for the staff team were witnessed by me, as researcher in the study, whilst the service-user signature was witnessed by both a staff team member and myself. This was in order to ensure that the staff member, who knew the service-user well, was signing to confirm that they thought the service-user had given consent based on a clear understanding of what participating in the study would involve. Once the consent forms had been signed the service-user and staff team entered the study. At this point, arrangements were made to begin the weekly music therapy sessions for the service-user. The SGFs, two arts therapists within our department who would be facilitating the monthly staff groups, made contact with the staff teams to arrange the staff groups.

4.4 The semi-structured interviews

4.4.1 Designing the semi-structured interviews

The design of the SSIs arose from a consideration of the original research questions, which themselves had arisen from the literature search. Addressing these questions and trying to gain an understanding of the participants' experience of self-harm required slightly different questions for the service-users and the staff teams. It also required the consideration of a different timescale for the service-users and the staff teams, as first mentioned in §3.1.1. The reason for this difference is because of difficulties highlighted at the study design stage by both speech and language therapy colleagues and the three men that trialled the participant information sheets, all of whom suggested that there may be potential difficulties for participants in remembering, with accuracy, details over

a four-week period. All advisors felt it would be easier for service-users to respond with a clear 'yes' or 'no' to a question that asked if they had hurt themselves on purpose during the last week. However, I did want to gain as broad a picture of possible about the frequency of self-harming, which was the reason for requesting a longer timescale in the interviews with the staff teams.

I am mindful that the questions about music therapy and the staff groups may seem more open than some of the other questions. This was intentional and I have used a mixture of closed and some rather more open questions to reflect the differences in the type of information that I hoped these SSIs would generate. In order to understand if the nature and frequency of self-harming reduced over time, it was necessary to ask some quite closed, factual questions about the number of incidences of self-harm within a given timescale. Similarly questions about how staff teams responded and whether the service-users found the staff helpful aimed to provide factual information. In addition to this type of information, I also wanted to understand, in a broader sense, what the impact of receiving music therapy or a monthly staff group meant for the participants. I felt that this needed a slightly differently worded question. I wanted to minimise how much my own thoughts and ideas were projected on to this question whilst also not wanting to make the question so narrow that I only discovered whether or not music therapy and the staff groups had been helpful. If the participants had found these helpful, I wanted to understand as much as possible what it was about the intervention that had made a difference. Therefore, the questions about music therapy and the staff groups are deliberately more open.

4.4.2 Topic areas and questions for the SSIs for service-users

Questions for the two service-user participants enquired about three main topic areas: self-harm, the staff team and music therapy. Service-users were invited to think about the number of occasions on which they had self-harmed over the last week. They were also invited to tell me how they had self-harmed, how they had been feeling before self-harming and how it had made them feel afterwards. These questions relate to the main

research question about any potential correlation between music therapy being offered to the service-users and a reduction in the frequency of self-harming.

The focus then shifted slightly and the questions enquired about the staff team and how they had responded to the service-user when they had self-harmed. Participants were invited to think about the response they had received from the staff team in general and more specifically from the member of staff who had responded to the actual incident of self-harm. Service-users were then asked about whether or not they had found the staff's response helpful. Questions about staff responses sought to address the secondary research questions about whether staff's attitude and responses towards the service-user's self-harming had changed. The answers to these questions revealed any changes in staff's understanding about the nature and impact of self-harm over the course of the research study.

The subsequent SSIs for both the staff teams and the service-users asked about music therapy: whether or not this was helpful and, if so, how; whether service-users felt able to express themselves through this medium, and, for the staff team, whether they thought music therapy was benefitting the service-user that they support. Questions about music therapy were not included in the first SSI because the intervention had not been offered at that stage. The second SSI was administered six months after the start of the study and the third SSI was administered twelve months after the study had begun. Below is a list of the topic areas and questions asked of the service-users:

Self-harm

- In the last week have you hurt yourself on purpose?
- Has this happened a lot of times, a few times or just once?
- How did you hurt yourself? What did you do?
- Do you know why you hurt yourself? It's OK if you do not know why you did it.
- Did you feel better or worse after you had hurt yourself?

Staff

- What did the staff do when you hurt yourself?
- Did you find the staff helpful?

Music therapy

- Do you think that music therapy has helped you? If so, can you tell me how it has helped?

4.4.3 Topic areas for the SSIs for care staff

The first topic area for the staff teams included factual information about the frequency and method of self-harm for their service-user during the last four weeks. This is in fulfilment of the first research question, which seeks to clarify whether there is a reduction in the incidences of self-harming over the twelve months of the research study. A subsequent topic area focuses on the impact of the service-user's self-harming on the staff team. Questions about how the staff team felt when their service-user self-harmed, how they understood why the service-user might have self-harmed and how they responded to it showed whether or not staff's understanding and responses changed over time. This addressed the secondary research questions. The third topic area asks about the interventions of music therapy for their service-user and the monthly staff groups for themselves. Answers to these questions allow correlations to be suggested between changes in the frequency of self-harming, changes to the staff team's understanding of and responses to self-harming, and receiving the interventions of music therapy and the staff groups.

The semi-structured interviews asked the following questions of the staff teams:

Factual information about self-harming

- Please describe to me the ways in which the service-user you support usually self-harms.
- During the past four weeks, how many times has your service-user self-harmed?

Impact of the service-user's self-harming on the staff team

- Do you always understand the reason why your service-user self-harms?
- Can you describe how you feel when your service-user self-harms?
- Within your staff team is there an agreed way of responding when your service-user self-harms, or does each member of the team respond differently?

Efficacy of music therapy and the staff groups

- Do you think music therapy for your service-user has been helpful? If so, can you say how?
- How have you found the staff groups?

Once participants entered the study and the arrangements for the music therapy and the staff groups had been made, the first of the semi-structured interviews (SSIs) was administered. At this stage the intention was to gather a baseline measurement of the frequency with which the service-user was engaging in self-harm, a sense of how this was understood by both the service-user and the staff team, how the staff team responded to the self-harm and whether or not the service-user found what the staff did helpful.

4.4.4 Administering the SSIs with staff teams

The SSIs for the staff team were administered in a quiet, private room within the multi-disciplinary team base. Six members of a possible nine members of the staff team came to the initial SSI for both service-users. The SSIs and the subsequent monthly groups were open to all members of the staff team. The SSIs were recorded, so that they could be transcribed verbatim and analysed; staff had already consented to this when signing the consent form. As discussed in §3.4.2.1, the SSI was administered to the staff team as a group. This was to reinforce the sense of the staff team as a cohesive group that worked together. I was also interested in learning about the team's shared experience of supporting their service-user that self-harmed and the ways in which that impacted upon

the team as a whole. By interviewing the staff as a team, I hoped to encourage a sense of openness within the team and to facilitate an atmosphere where the staff could express themselves and hear about the feelings and experiences of their colleagues within a mutually supportive setting. I am mindful that some of the questions invited an individual, rather than a collective, response: for example, the question of how the service-user's self-harming had made them feel and how the staff had responded to the self-harming incident. These questions generated a wide variety of responses unique to the individual staff member but it did offer some insights into areas of congruence and divergence among the staff team. It also highlighted how differently individual staff members responded to an incident of self-harm, meaning that the service-user might have encountered a variety of reactions and responses to his or her self-harming depending on the staff member who responded to it.

4.4.5 A small clinical vignette to illustrate the method

An illustration of conflicting responses to an episode of self-harm from different staff members within the same staff team occurred when participant B had self-harmed, injuring his ankle: one staff member wrapped the ankle in a bandage; another staff member cut the bandage off, deeming it unnecessary and serving to draw attention to the injury which he thought was what the service-user wanted. These two very different responses by members of the service-user's staff team highlight the ways in which the staff's responses are influenced by the beliefs they hold about the reasons why the service-user self-harmed. This is concordant with the outcomes of the Q-methodology study discussed in §2.8.

4.4.6 Conducting the SSIs with service-users

In accordance with the SSIs for the staff teams, the SSIs for the service-users were also administered in a quiet and private room within the learning disability team base. Only the service-user and myself present. The SSIs were recorded. This had already been explained to the service-user when the participation information sheets had been presented; it was also one of the statements on the consent form which the service-user

had signed. In the room, I explained that the purpose of the recording was to help me to remember and think about the things that the service-user had said. It was explained that there were no right or wrong answers to the questions and that if it was difficult to think about any of the questions, that was fine and we would simply move on. It was also made clear that their answers would not be shared with the staff team. Both participants seemed comfortable with this and were able to articulate their experiences with clarity.

4.5 Semi-structured interviews, data collection and analysis

4.5.1 Preparation of data

This section describes the method for collecting and analysing the data. The data for this study was generated by the semi-structured interviews, each of which was transcribed verbatim, producing a lengthy transcript for each interview. In order to prepare the data for IPA the transcripts were read and then annotated to reflect the sometimes conversational style of the participants. Hesitations were represented by 3 dots (…), for example, 'it's sometimes…like…you know…' and any words that could not be discerned or where two or more staff members were speaking at once and the words were not clear were indicated by the word 'unclear' in brackets in the transcription. Any identifying data or references to names were eliminated to ensure confidentiality was maintained. Each transcript was then checked again against the recording to check for reliability, to correct any errors and add any missing or unclear words in order to create as full and honest a transcript as possible. Smith and Osborn (2008) suggest that Interpretative Phenomenological Analysis (IPA) is very compatible with the semi-structured interview method and that this combination provides the researcher with rich and complex data.

4.5.2 Conducting the IPA

Once the semi-structured interviews had been transcribed, each transcript was read through four times to ensure that as much significant material as possible was captured.

The first reading attempted to gain an overall impression of the experiences of the service-user and their staff team. The transcripts were then read through a further number of times and anything noteworthy was annotated in the left-hand margin. At this stage the aim was to capture anything that seemed significant or interesting. This ranged from the use of language, tone, detailed descriptions and, in the staff groups, contradictions, disagreements and similarities of viewpoints. Significant material included anything that related to the research questions and any direct answers to the SSI questions particularly relating to the frequency or method of self-harming. I also tried to capture the emotion expressed by the service-users and staff teams in these transcripts; anything that was emphasised or expressed with a particular strength of feeling was noted in the margin. Self-harm is an emotive subject area and it was interesting to note the amount of emotion that emerged in these transcripts, particularly when they were being listened to and initially transcribed. This seemed an important and significant aspect of the data and therefore worthy of being captured. I am mindful that the emotional aspect of the transcripts shaped, and therefore contributed to, my interpretation of the data. There were twelve transcripts in total: three for each service-user and three for each staff team. This process was carried out for each of the transcripts. Here, in Table 4.2, are two examples, the first from participant B's staff group and the second from participant B himself. The transcript is on the right and general observations were made in the left-hand column:

can't think of everything think about what Derek needs attack with military precision have to do it being told what to do by staff breaks an object	*'So, you can't think of all the things that could possibly happen so you think: "OK, he needs to have his toothpaste"then you think: "Argh, right, let's think"...at which point am I gonna attack all this so it's like a...it's like a military, precise operation that you have to do.'* *'Then: "You mustn't stand on the settee."Yeah. "You mustn't stand on the settees" That's it - she told me to get off. Went straight like that." (mimes punching a photo frame and breaking the glass)*

Tab. 4.2: Extracting the themes

The comments on the left are observational and factual: they reflect the text and are summarising or paraphrasing what is in the transcript.

4.5.2.1 Emergent themes

In the right-hand margin, what Smith and Osborn refer to as 'emergent themes' (Smith and Osborn, 2008, p. 69) were noted. Once the emergent themes were annotated, any connections between these themes were observed and the transcript re-read to ensure the integrity of the themes against the transcript and also to make sure that they captured a true representation of what had been said in the original interviews.

The emergent themes, noted in the right-hand margin, tend to be more abstract than the first observations that were noted on the left. There is an interpretative element to the annotations in the right-hand margin but the comments still stay faithful to the original transcript. Here, in Table 4.3, is a further example from participant F's staff group:

(Staff member L): 'It's very frustrating, because…we'll turn up and there will be pee all down her leg and what' s really upsetting is…you know it's almost better and we have done the care: we change the bandages, we've done the dressings, we change the gloves, we really go all out to make that leg better and she says: "Does it look alright?"and I say: "No, it looks like a squashed hedgehog on the road. It's disgusting, Jackie"and then you sit there and you are so depressed, you're almost in tears yourself. She picks up on this…and there are tears in her eyes as well.'	sabotaging of staff's efforts L expresses own sense of repulsion by describing Jackie's leg as looking like something dead Jackie very attuned to L's reaction

Tab. 4.3: Extracting emergent themes

In this extract, the comments in the right-hand margin used some degree of interpretation and abstraction compared to the left-hand margin comments in the first transcript example. The initial observational comments were transformed into the emergent themes which are now notated in the right-hand margin. The whole transcript was treated in this way and the emergence of similar themes throughout the transcript was noted.

4.5.2.2 Clustering the themes

Once the whole transcript had been read and initial notes transformed into emergent themes and noted in the right-hand margin, the next stage of the analysis involved extracting any connections between the emergent themes. Smith likens this to the pull of a magnet:

> 'Imagine a magnet with some of the themes pulling others in and helping to make sense of them.'
>
> (Smith, 2008, p. 70)

The emergent themes were first listed on a piece of paper in chronological order, in other words, the order in which they were noted in the transcript. Clustering the themes was done by analysing the emergent themes, looking for any connections between them and noting any emergent themes that naturally clustered together. The themes were clustered according to how the themes fitted together. Themes which had similar understandings, concordance or parallel meanings were grouped together; those in opposition to each other were placed at opposite ends of a spectrum. When clustering the themes, regular references were made to the original transcript in order to preserve the integrity of the original text by making sure that the cluster themes reflected the words of the participants. This required a combination of adherence to the transcript so as to faithfully represent what the participants said whilst also using one's own understanding and interpretation to make sense of what the participant was saying. As the cluster themes were drawn out, references were made to phrases that the participant said which related directly to the theme described.

4.5.2.3 Superordinate themes

The next part of the analysis involved producing a table of superordinate themes. Identifying and grouping the clusters allowed for the clusters themselves to be given a name or theme: this is known as the superordinate theme. The table below lists the superordinate themes and the cluster themes that go with each superordinate theme. Each theme is illustrated by a small identifying piece of text, what Smith calls an 'identifier' (Smith, 2008, p. 72) from the transcript. The identifier gives key words from an extract of the transcript with the page and line number, to illustrate the cluster theme. This helps to show where examples of each theme can be found in the text, as the example below shows:

grieving	3.5 'I miss me mum, that's what it is'
(3.5 = page 3, line 5 of the transcript)	

The superordinate themes can be described as the headings given to each group of cluster themes: a word or short phrase that summarises what the cluster themes have in common and explains why they were grouped together in a cluster. Once this had been done, examples from the original transcript were then added as quotations to illustrate the cluster themes and a table was made to reflect each superordinate theme with the corresponding group of cluster themes underneath. It is important to say that each transcript was treated independently of the others to ensure the integrity and authenticity of each individual transcript. I also wanted to ensure that any commonalities between the transcripts were not as a result of any bias from comparing the transcripts during the analysis. Once all the transcripts had been independently analysed, two final master tables were constructed, one for the service-users and one for the staff teams, showing the overall superordinate themes. These were chosen for how prevalent they were across all the transcripts and the number and quality of the examples that illustrate them. The final master tables are shown in §6.5 and §6.8.

4.5.2.4 An illustration of clustering the themes

Figure 4.3 illustrates the process of clustering the themes from Janet's transcript.

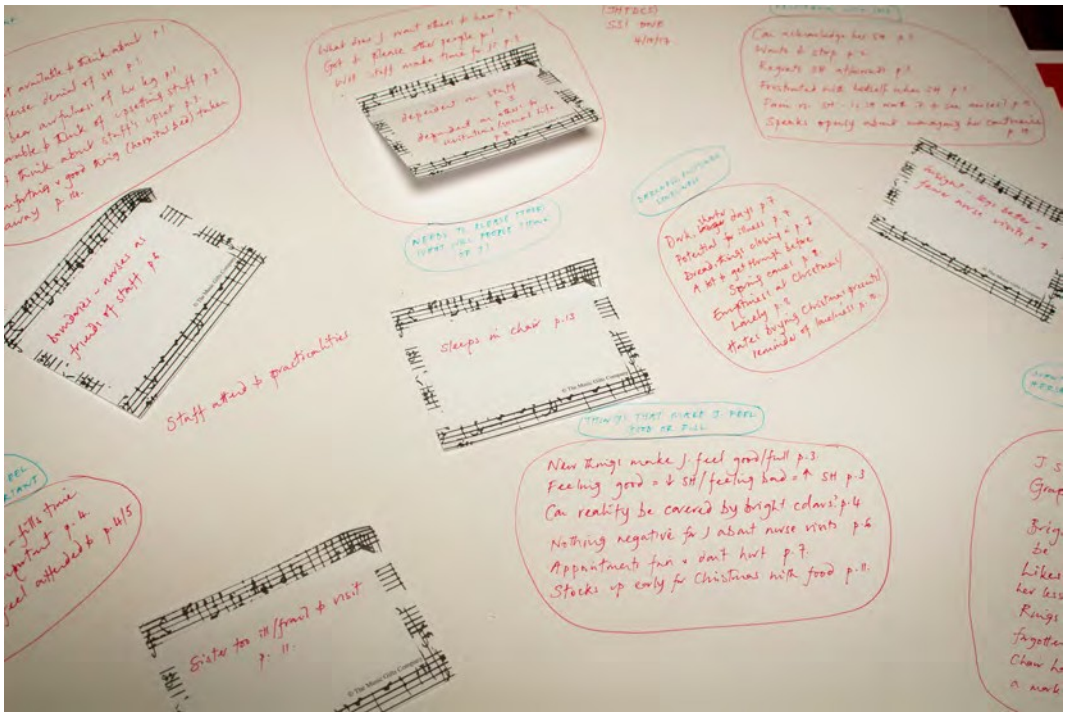


Fig. 4.3: Clustering the themes

4.6 Data storage

During the transcription and then the preparation of the transcripts for analysis, all material was stored in a locked facility within the researcher's place of work. When the data needed to be moved for the purpose of working on it at the researcher's home or at Anglia Ruskin University library, the researcher used a portable and lockable storage facility. This was in compliance with the United Kingdom Data Protection Act 1998.

4.7 Music therapy sessions

This section describes the music therapy sessions offered to each of the participants in this study. It includes a description of how the room was arranged and the types of

instruments available as well as how the service-users were invited to use the sessions. This will be further elaborated upon in the case studies in Chapter 5.

4.7.1 Setting up the music therapy room

Both participant B and participant F attended once-weekly individual music therapy sessions for a year. Each session was of 45 minutes' duration and happened in a quiet room within the multi-disciplinary team base. The room contained two comfortable chairs and a small table. The following instruments were available: keyboard; guitar; a variety of drums and cymbals, both standing and hand-held; metallophone; xylophone; glockenspiel; wind chimes and a large array of smaller hand-held percussion instruments, such as shakers, maracas, claves and guiros. Larger instruments were placed around the edge of the room, with the smaller instruments arranged on the table. The music therapy sessions were recorded as described in §3.1.1.

4.7.2 Autonomy and independence

The service-users were encouraged to direct and use the sessions in the ways that were most helpful and meaningful to them. There was no agenda or structure to the session and service-users were invited to use the available instruments, including their voices, and also speech. During the first session, I reminded the service-users about music therapy and their participation in this research project about self-harm. I described music therapy as a space where we could think about feelings and play music together: a place where there are no right or wrong answers or ways to play, but instead somewhere to explore and perhaps try out new things. After this, and for all subsequent sessions, I tended to be quiet at the start of sessions so as to minimise my influence over the material that would be generated by the service-users in the sessions. In the following section I will describe some of the clinical interventions that I use in my practice of music therapy.

4.8 Clinical interventions in music therapy

A number of clinical interventions were offered during music therapy sessions. These included co-improvisation, the use of pre-recorded songs, vocalising, composition and the use of music as a strategy to manage the impulse to self-harm at home. Table 4.4 shows the clinical interventions that each participant chose to use.

Participant	Co-improvisation	Pre-recorded music	Vocalising	Composition	Use of music at home
B	✔	✔	✘	✔	✔
F	✔	✘	✔	✔	✘

Tab. 4.4: Clinical interventions chosen by participants

There will be further discussion about the clinical interventions offered during music therapy sessions in the case studies, illustrated in Chapter 5.

4.8.1 Co-improvisation

As described, the room was set out with a selection of tuned and untuned percussion instruments. Both participants seemed to find it difficult to initiate a co-improvisation within the sessions. They each connected small percussion instruments to negative memories of music-making at school and participant F was worried that if she played if might make her seem 'babyish'. For participant B, it was also the smaller percussion instruments that he most associated with the negative memories of school music-making; the drum and cymbal reminded him of an uncle that had played in a marching band. This more positive association enabled him to approach these larger instruments, eventually leading him to bring his own guitar to the session to co-improvise with me.

4.8.2 Pre-recorded music

Participant B collects CDs and has a large collection, mostly of pop music of the 1960s and 1970s. He enjoys visiting charity shops to buy them and he will then trade them or swap them with his fellow tenants. He also had a large, portable stereo with colourful flashing lights and a remote control that he often brought to music therapy sessions. A sample of CDs were brought to the sessions in a large case with clear sleeves and he spent considerable time flicking through the collection. As with his co-improvising, the focus, at the early stage of the work, was on finding the 'right song'. It was not clear to me what constituted the right song but it was noteworthy that participant B would put in a CD and play a few seconds of the first track before forwarding on to the next; then he would repeat this until the whole disc had been heard (but only in tiny fragments). A new CD would then be played and the process repeated.

Participant F did not use pre-recorded music in her sessions.

4.8.3 Vocalising

Participant B did not sing or vocalise during his sessions. For participant F this was a significant part of her music making although it did not develop or change very much over the course of the therapy. Participant F was drawn to untuned percussion instruments, particularly guiros and other instruments that could be scraped. I was interested in this because of the way she self-harmed, which was to aggravate badly ulcerated and often infected legs by sticking sharp implements down her bandages to scratch them. Her music echoed this and was scratchy and irritable; she once described our co-improvising as sounding like a cat clawing at wallpaper. Underneath her guiro playing, she could be heard to produce almost imperceptibly low, guttural sounds. These also sounded 'scratchy' in quality and I felt she wanted to keep these sounds hidden, rather like her leg wounds, which she tried hard to keep from staff. Over the course of the music therapy, her vocal sounds began to become slightly louder but she was not able to significantly change the quality of these sounds.

4.8.4 Composition

Both participants engaged in composition to some extent. For participant F this was a less significant part of her music-making but there were certain periods of the year, such as Christmas, when she would want to compose a piece during her session. This was always confined to just one session and, like an improvisation, it was not consciously re-visited or expanded upon in any way. For participant B composition was a much more consistent part of his music therapy sessions. He would often speak of making up a piece for his parents (both deceased). He would spend time trying out the different voices on the keyboard and often chose something like a church organ or a choir sound. He would think about and tell me the character of the music he wanted to create and together we would try out different things until he found something that expressed what he wanted to say.

4.8.5 Music as a strategy to manage the impulse to self-harm at home

For participant F, music did not seem to have a particular significance for her outside of the music therapy sessions. She told me that she did not often listen to music at home, much preferring to watch television and DVDs. For participant B, music was an extremely important part of his life and outside of the music therapy sessions he took an active interest in music. He had a long-standing interest in collecting CDs and had, for many years, enjoyed spending time in his bedroom, on his own, listening to music. Before participating in this study, the staff team had encouraged participant B to listen to music when they sensed that an episode of self-harm might be imminent. They were attuned to the idea that music was a potentially calming influence for him. During his music therapy, participant B discovered that the physicality of playing music also helped him to feel better. There were occasions when he arrived at music therapy in a heightened state, having had an argument with one of his fellow tenants. His physical tension was very palpable and sometimes he had already self-harmed before arriving at his music therapy session. He would often go straight to the instruments at these moments, usually the keyboard, and initially he would turn up the volume on the keyboard and select the loudest ‘voices’ on the keyboard such as the organ, choir and

string sounds, and map them on top of each other so that the resulting sound was completely cacophonous and incoherent. Once this had been sustained for several minutes he began to withdraw the different voices one by one until he was left with a single-line melody. As he did this, it was possible to see the tension in his body gradually dissipate. Often at the end of his playing he would say: 'That feels better; I needed that.' We were able to identify that the physical act of playing music lowered his stress levels. Since he had a guitar at home he began to play this in his room as a way of helping him to relax.

4.9 Staff group sessions

The ideas from the GAM concept, discussed in §3.7.6, have been helpful as a framework within which to think about the two staff groups. Foulkes, describing small groups, says that:

> 'If they function and perform together as a group, as a "team", the improved function of the whole group is the task. Thus the group itself becomes the foreground and the individuals are seen as background.'
>
> (Foulkes, 1975, p. 8)

The SGFs and I were interested in how the staff teams functioned as a group, particularly in relation to their service-user's self-harm. The groups occurred once a month for one hour and a core group from the staff team attended. The SGF and I acknowledged the practical difficulties for staff members to commit to this, finding a balance between attending the monthly groups and ensuring there were still staff available to work while the groups were in progress. This issue is discussed more fully under the limitations of the study in §8.3.3. It was intended that the membership remain as stable as possible but the groups were set up as slow open groups, meaning that it allowed for membership to change slowly over time. In both groups, there were small changes to the group membership over the twelve monthly groups.

4.9.1 Setting up the staff groups

The staff groups took place within the MDT base in a quiet and private room. Chairs were arranged in a circle to facilitate conversation and interaction. Once the group members had arrived and the group had started, the facilitators began with a general enquiry about how things had been in relation to the service-user and their self-harming over the last month. Both facilitators found that the groups needed little encouragement to talk. The group was encouraged to talk freely and the facilitators commented on what they observed, sometimes to seek clarify and at other times to gently challenge or explore.

4.10 Summary

This chapter has discussed the method for this research study: a small qualitative study analysed within the framework of Interpretative Phenomenological Analysis. Data collection was gathered using semi-structured interviews, the method for which has been discussed in this chapter alongside the method for analysing the data. The results of this analysis will be discussed and presented in Chapter 6.

Chapter 5: Case Study of Participants B and F and their Staff Teams: the Process through which the Data was Gathered

5.1 Introduction

This chapter describes case studies of the two service-users and their staff teams that were recruited to this research study. It demonstrates the clinical processes through which the data was generated. The service-users, whom I shall call Derek (participant B) and Janet (participant F), received individual weekly music therapy sessions for one year. Alongside this, their staff teams received monthly group sessions for one year, with an arts therapy colleague (a different colleague for each staff group owing to geographical implications) who acted as a SGF in this study. I will summarise the music therapy sessions and then the staff groups, drawing parallels between the themes that emerged in these two domains of work. Both service-users and staff teams consented to this work being used for academic purposes: this included being written about, published and presented at conferences; all names are changed to maintain anonymity and any identifying data is not used. Any words in single quotation marks and in italics represent words spoken by either the service-users or members of their staff teams.

5.2 Case study 1: Derek

The youngest of two brothers, Derek is 57 years old and grew up in a rural location with his parents and an older sibling. He has mild-to-moderate learning disabilities and lives in a small group home with two other people. They were supported by a full-time staff team which includes a rota for a sleep-in member of staff. Derek described his childhood as happy and recalled a close relationship with both parents. Despite tensions between him and his sibling throughout childhood, Derek described them as '*getting on all right most of the time.'* The family was well known in the village and Derek would

often walk the family dog on his own, greeting people he knew and stopping for conversations. This opportunity for independence was important for Derek and he remembered these interactions with friends and neighbours with great warmth and fondness. Derek's father died approximately fifteen years ago. He remained living with his mother until her death about ten years ago. Following that, and in middle age, Derek left home for the first time, moving into a respite care centre where he remained until moving into his current accommodation eight years ago.

5.2.1 Derek's interests

Derek is a warm, outgoing person who can express his opinions and articulate his needs. He has a great capacity for social interaction; he is friendly and interested in other people. He will ask people how they are and remembers details about them. I have noticed that when Derek was in the department he would talk to other clinicians in the team if he passed them in the corridor and enjoyed the warm responses he received. He liked days out with members of his staff team, in particular travelling on the train to visit churches and cathedrals. He was especially drawn to the sound of a church choir, something he remembered from going to church in childhood; he describes it as peaceful and relaxing.

5.2.2 History and origin of Derek's self-harm

Derek also had a chronic history of self-harm which included breaking bones, interfering with wound-healing, cutting himself with broken glass, kicking his legs against hard surfaces until they bruised and rubbing his legs with a towel, causing red marks and open wounds. The onset of Derek's self-harm coincided with a deterioration in his mother's health. As her health began to decline, Derek became her carer until she died in the family home in her late eighties. As Derek's self-harming became more prevalent, it came to the attention of health professionals who were becoming involved in supporting Derek as his mother's health declined.

5.2.3 Jigsaw puzzles and electrical items

Derek had a long-standing interest in doing jigsaw puzzles and taking apart small electrical items. I mention these together because common to both is the notion of taking something apart and not being able to put it back together again. With electrical items he would take apart a few gadgets at a time, mix together the components and then struggle to make something fit together. Similarly, with puzzles, Derek would mix together pieces from several different jigsaw puzzles on to a table and then try to force together a picture from this, often banging together pieces that did not have an obvious fit or belong together. Staff acknowledged that they found this very difficult to cope with and were not always able to resist the impulse to tell him he had got it wrong. In the monthly staff groups, they were able to explore how hard they found it to see him trying to bang the wrong pieces in to force a fit. It was difficult for them to accept that Derek had a different version of the puzzle in his mind and that although his version did not correspond to their correct version, it was nevertheless meaningful to him and therefore valid. During music therapy, Derek would express his frustration about the staff telling him he had put the wrong puzzle pieces together. When staff tried to intervene this could lead to a sudden explosion of anger and an incident of self-harm.

5.2.4 A clinical vignette

Six weeks into the research project, Derek arrived for music therapy with a completed jigsaw puzzle which staff had helped him glue on to a piece of backing cardboard. It came at a time when Derek's methods of doing puzzles and the staff's frustration with this was being thought about in the staff groups with the SGF and when Derek was layering the various voices of the keyboard to produce a loud, incoherent sound during music therapy sessions (this will be discussed in §5.4.3.1). The sudden arrival of something complete, coherent and finished was striking and seemed incongruent with the more chaotic material that was appearing both in the music therapy sessions and the staff groups. The fact that one of the staff members had stuck it down so it could not come apart again seemed particularly significant, given their difficulties with accepting Derek's methods of doing a jigsaw. It felt somehow as though having finally got it right

and completed a puzzle it had to be glued together so it could not become mixed up again. Perhaps there was also an unconscious wish to immortalise something that had gone well. I wondered how much of it Derek had actually done but he expressed great pride in it and we kept it up in the music therapy room during his sessions, Derek having chosen a place for it to be displayed.

If we consider the need to mix up jigsaw pieces and electrical components within a psychoanalytic framework, it could possibly be understood in the following way: that at a time when he was facing the decline and eventual death of his mother, Derek appeared to be showing something of his internal world where perhaps nothing made sense or joined together anymore: in other words, he could not put all the pieces back together. Considered through the perspective of having a learning disability and Derek's own admission that sometimes his brain does not work properly, it can also be seen as a possible communication about his own sense of not feeling right, or even of feeling that somehow he is not wired together properly.

5.3 Introducing the Juniper Close staff group

Juniper Close is part of a larger charity that offers group homes, community support workers and respite care placements for adults with learning disabilities across the UK. This particular house is small with a garden and offers accommodation to three people who range in age from their early thirties to their late fifties. The house is staffed by a mixture of people: those who have worked within the service for many years and refer to themselves as *'old-timers';* those (often younger members of staff) who stay for a couple of years before moving on; and newly recruited members of staff and relief staff who cover shifts when the house is short-staffed. For Derek and the other people who live there, this represents an ever-changing picture of care staff.

Just before the start of the monthly staff groups, one of the team leaders, who had worked at Juniper Close for many years and knew the service-users well, left. This came about rather suddenly and was part of an internal organisational shift to provide staff and managers to other group homes within the charity. For Derek and the other

residents, it meant a very sudden goodbye to a member of staff of whom they had grown extremely fond. For the staff, it served as a reminder that it was the managers above them who had the power to take the decisions: in the staff group they spoke of their anger at feeling *'done to'* by managers who made important staff decisions that affected the house but did not have to experience the consequences of an unsettled service or the impact on the service-users that lived there.

Each change of staff brought about a shift in the culture of the house. The history of the service-users had to be learnt by the new staff, as did their understanding and knowledge of them. For both Derek and his staff team, issues of powerlessness were significant.

The staff team made a strong commitment to the monthly staff groups that were offered as part of this research study. The group had a relatively stable membership, with a core group of four members plus two staff members who left during the group and two new members of staff who joined part way through. The membership consisted of two older men who had worked in the service for many years, middle-aged and younger women who were much newer to their roles and an experienced female team leader. The research assistant who facilitated this group described them as chatty and humorous, with much of the conversation being dominated by their team leader who often assumed the role of spokesperson for the group.

5.4 Music therapy with Derek

In this section, I will describe the music therapy process with Derek and reflect on the external framework around the music therapy sessions, including the journey to and from the music therapy room and the interactions with staff members who brought Derek to his sessions.

5.4.1 Journey to the music therapy room

Derek attended weekly music therapy sessions for one year as part of this research study. Initially Derek engaged well with the work. He arrived promptly and was keen to play music. As he entered the department he would greet other members of the team, often passing the time of day or trying to initiate a bit of a joke with somebody, usually by pretending to trip over or walk into something. Although not self-harm as such, I was interested in how Derek used the *potential* to possibly damage himself in some way as a means of humour and a way to engage with people. The staff team also reported that they thought Derek might use self-harm as a way to 'gain an interaction'. So the framework around the therapy included the journey from the waiting room to the therapy room, the concept of a potential injury, a feigned limp, Derek rising stiffly from a chair with the comment *'I'm getting old, you know'*. Derek is anything but the figure of an archetypal old man: tall and lean with an upright posture and a good face, he dresses in a fashionable way and takes care of his appearance. He keeps fit by cycling and going out for long walks. Yet he also needs to present a different image of himself: that of a stiff, elderly man who struggles to get out of a chair, someone with aching joints, a sore back and a limp. I became curious about this version of Derek. It frustrated the staff who saw it as false, a deception used to gain sympathy and attention. But as he limped along the corridor to the therapy room, speaking loudly about being an old man, this became the basis for a light-hearted interaction with another clinician or a member of administrative staff. Without this, it would simply have been a rather prosaic walk from the waiting room to the therapy room. Whilst it was not especially exciting or dramatic, it did give him a vehicle through which other people acknowledged him with warmth, concern and humour. Above all, it ensured he was noticed and validated and it became clear how important this was for Derek.

5.4.2 Three phases of Derek's musical journey

Derek's musical journey has been interesting and falls quite naturally into three distinct sections. In phase one, the first three months, Derek and I seemed to be focusing on two main musical tasks: one seemed to be about finding a way to understand Derek's

music as an expression of his internal world; the second was concerned with finding a way for Derek to feel musically held in order that he could process some of his more difficult experiences without re-experiencing the painful emotions that accompanied the original trauma. Musically we found ourselves in a seemingly relentless search for what Derek thought of as the *'right'* sound. His eye contact with me was sustained to the point of being uncomfortable and I was aware of feeling musically smothered by Derek's use of the different voices of the keyboard to layer one sound on top of another until it became so cacophonous that my own music became inaudible. In exploring these two musical tasks I will draw some possible connections between Derek's music and a number of psychoanalytic concepts that were described in §3.7 as underpinning my clinical practice. These include a musical manifestation of transference and countertransference, the concepts of containment and holding within therapy, as described by Bion and Winnicott respectively, and finally something about Daniel Stern and his concept of affect attunement.

5.4.3 Phase one; task one: Derek's music and its links to aspects of psychoanalytic theory

5.4.3.1 The music and possible transference connections

When Derek first came to music therapy, he experimented with layering the different voices of the keyboard: he would often begin with the organ sound, producing a lot of notes and chords that he held in the pedal, before changing the keyboard sound to strings or voices and mapping them over the top to produce a cacophony of sounds. It was impossible to hear the individual voices any more and the resulting sound was indistinct, extremely loud and painful to listen to. Referring back to Freud's definition of transference in §3.7.2 allows for consideration of the ways in which a patient might map on to the therapist feelings or attributes belonging to a past figure, usually a parent, to produce a new, somewhat confused re-emergence of these feelings towards a person (in this case, the therapist) in the present. There seems to be a possible parallel here with what was happening in Derek's music. Given the range of voices available on the keyboard, it was significant that Derek repeatedly chose the sound of a church organ

and a choir, sounds that had very meaningful resonances from his childhood. In their musical re-emergence in the present with me in the music therapy encounter, these sounds became mapped on top of each other to produce a sound that was distorted and grotesque. As the sounds built up on top of each other and Derek increased the volume, the organ sound took on a 'horror' quality, with the voices, often played in the upper register, sounding like screams. The music had a frightening, death-like quality to it and I was reminded of Derek's descriptions of his mother becoming thin and bony and of his own panic at watching her die. Trying to understand this musical communication within a transference framework made it possible for us to begin to explore some of his unprocessed feelings of grief, fear and rage. Streeter's ideas about the ways in which what the patient expresses in words can mirror how the musical material is constructed in relation to the therapist (discussed in §3.7.2.1) come to mind here. Derek's music seemed to correspond to what he said in the first SSI:

'*I miss me mum, that's what it is*.'

5.4.3.2 The music and its connection to countertransference

I sometimes experienced a strong impulse to leave the room. In countertransference terms it could be considered that I was in touch with something of how Derek felt, watching his mother die, perhaps wanting to run away from the situation but not wanting to abandon his mother. There was a paradox between wanting to stay with Derek and with what he was showing me but also feeling repelled by it. My attempts to make a musical response felt unsatisfactory: nothing could penetrate the wall of sound that Derek was building up and I felt musically incompetent and useless. To consider this within Streeter's framework, it could be seen as another manifestation of countertransference: my own feelings of not being able to do anything apart from witnessing the sound that was being produced in the room resonating perhaps with Derek's feelings of helplessness in the face of his mother's death. The music physically hurt my ears and we were able to use this to explore the ways in which Derek's mother's decline in health and eventual death caused Derek significant hurt and pain. He described his mother as becoming *'thin and bony'* and became tearful as he recalled

this. If we consider that the emotional pain of this was too much to bear for Derek and difficult to share with others, then self-harm, a physical wound that at least was within his control and could be more readily seen and attended to by others, might start to make sense. In the first SSI Derek spoke of going to the hospital with a sense of drama and possible excitement. He was also preoccupied with how he might maintain the injury (by interfering with wound-healing) in order to bring about a return visit to the hospital and ensure he continued to be attended to.

5.4.3.3 Derek's music and Bion's concept of containment

As discussed in §3.7.3, the term 'containment' is often used by therapists to describe an aspect of the therapeutic process in which patients project their unmanageable feelings on to the therapist. The therapist listens, absorbs and reflects upon these feelings and can re-introduce them back to the patient in a more manageable form. The patient can then re-experience them as more tolerable because they have first been tolerated and survived by the therapist.

Keeping this idea in mind and returning to Derek, it is possible to see how Derek was, through his music, projecting in to me feelings about his mother's illness and death that he still experienced as unmanageable. The instinct to escape from his music was ultimately what showed me the necessity of remaining with Derek's music and, in Bion's words, to listen, absorb and reflect upon it: in other words, containing Derek's music with all its discordance, confusion and pain.

When Derek was mapping the different sounds on to the keyboard in such a way that I felt musically incompetent, it seemed that he was projecting into me the unbearable part of him that had felt helpless as his mother was dying. I received this in the countertransference as an awareness of my own difficulties in making any kind of musical connection with Derek's music. Becoming more aware of this enabled me to gradually find ways to match the intensity and volume of Derek's music by providing a firm harmonic structure. I hoped that a solid and strong musical framework enabled

Derek to feel musically held so that he could process and remember his mother's death without re-experiencing the traumatic feelings of loss he had experienced at the time.

Within music therapy sessions, Derek was able to describe another, more literal way in which he felt uncontained: when he had self-harmed the bleeding was sometimes difficult to control.

5.4.4 Phase one; task two: finding a way for Derek to feel musically held

The concept of holding was first described by the psychoanalyst Donald Winnicott (1896–1971) and was described in §3.7.4. Other analysts, including Patrick Casement, have also offered helpful definitions of this concept, also referred to in §3.7.4. As well as trying to understand the ways in which Derek's cacophonous music seemed to be a musical way of him projecting into me his feelings of impotence and helplessness, it was clear that I needed to find a musical way of holding him by providing something that felt musically comforting and safe. One way of doing this was to try to find a musical way of containing the chaos. Interestingly, in sitting at the keyboard, Derek had taken possession of the loudest instrument available to us; my attempts to match the intensity of Derek's music by making a big, strong, structured sound of my own were scarcely audible. This meant that I needed to find another, different way of holding Derek in the music, an alternative way of being present with him in the music, rather than simply looking for a way to contain the intensity of his sound.

Initially, Derek's music (the representation of his chaotic internal world into sound) and my difficulty in finding an adequately containing or holding musical response, resulted in an early misattunement between us.

5.4.4.1 Musical attunement

Finding a way to musically attune to Derek was what ultimately seemed to enable him to feel more musically held during the sessions. Derek went to the keyboard and I invited him to choose something for me to play. I wondered if, by him choosing an

instrument for me, it might allow us to find some musical mutuality as well as creating a musical space for me. Interestingly Derek chose a large bass metallophone. Its tones are warm, deep and enveloping. Its sound suggested to me something womb-like, maternal and comforting and I was interested that this was what Derek had chosen. This musical encounter was different from anything that had happened previously: Derek did not use any of the voices on the keyboard but used the piano sound to play a single-line melody. It was sparse, sometimes hesitant and reflective. Above all, it was a sad, lonely melody in which I found there was space for me to offer a musical response, using my voice and the bass metallophone to attune to Derek and his music. When the music finished there was a silence and the music seemed to be held in the air for a moment before Derek said: *'that was for my mum'*.

5.4.5 Phase two: guitar playing

If we consider the first main phase to be about Derek's need to test both me and also what might be possible within the session, establishing a safe rapport both musically and psychotherapeutically and trying to find what he thought of as the 'right music', the second phase (lasting from month four to month nine) was concerned with Derek's increasing capacity to use the music to share aspects of his emotional world with another.

5.4.5.1 Derek's guitar

Four months into our work together, Derek told me that he had a guitar at home and wondered if he might bring it to the session. I was keen to encourage this and Derek arrived, rather proudly, with this very special object to him. The most immediately notable thing about his guitar was a very large dent in it which I later learned from staff had been as a result of Derek throwing it against the wall when he was angry. This corresponds to Derek's descriptions in the first SSI of how suddenly angry feelings could overtake him:

'*it* [feeling angry] *just came over me, just like that, it did*.'

However, what he also needed to tell me was how well he looked after his guitar, that he had had it for a long time and that he polished it every day. I was interested in this new object that Derek had introduced into the sessions and the meaning it held for him. He told me that his dream was to perform at a famous London venue in front of a large audience. It was very moving to hear him express his desire to be admired and for people to hear him play and to think he was, to use Derek's word, *'good'*. It also suggested a rather more painful sense that Derek did not feel good enough as he was. In other words, if he was not performing in London but was at home self-harming and pulling down the curtains, would he still be acceptable or good enough?

Derek had a very gentle guitar-playing style. He holds his guitar in a left-handed way, using his left hand to gently pluck the open strings whilst holding his right hand over the strings at the neck of the guitar. He would want me to accompany him on the keyboard. This music, which we could describe as the second phase of Derek's music, was very different from the keyboard music that Derek used to play at the beginning of our work together. He was still concerned with finding what he called the *'right sound'* and could soon become flustered and frustrated if he felt that his music was not right. It was striking that Derek chose to express his dissatisfaction in such potentially pejorative terms. He was unable to think about what right or wrong in the music actually meant or felt like, but it did seem to fit with some profound sense that Derek had of himself as *'wrong'* or just *'not right'* in some way. I wondered whether this was related to his sense of himself as a middle-aged man with a learning disability. Interestingly he was not able to be open to the idea that something between us in the music did not feel right, or that maybe my music was not right for what he needed; it was always *his* music, and therefore *him* that was wrong.

These co-improvisations, Derek playing guitar and myself at the keyboard, were much quieter, more lyrical and gentle. Derek often looked very emotional, sometimes close to tears. It felt as if he was close to being in touch with something very sad and, just at this point where he seemed close to tears, he would appear to trip up on the guitar string and the music would stop. He would often say something about catching his finger on a string or the guitar tripping him up in some way. What seemed significant here was that

once the music had stopped it could not be recovered. There was no sense that any mistake, mishap or temporary moment of disconnection could be survived. It felt that Derek was beginning to take some musical risks in terms of playing in a much more exposed way and with greater emotional expression, but when something went wrong as he saw it, e.g. he tripped up on a guitar string or caught his thumb in a string, this represented a rupture to the music from which recovery was not yet possible. This meant that the music often stopped very abruptly on an unresolved note or chord and I was mindful that Derek often looked pained by this. This reminded me of the ways in which Derek could be similarly pained when he self-harmed. I was interested by the idea that both an unresolved chord and an open wound are perhaps both seeking some kind of resolution. It was hard for Derek to imagine that we might simply have picked up the music again and carried on towards a different, more musically satisfactory kind of an ending. Similarly, when he was overwhelmed by his feelings, it was difficult to imagine any other outcome other than self-harming. Around this time, Derek broke his arm through self-harming and missed a session due to needing surgery to have his arm pinned together. This was a very distressing episode for both Derek and the staff team. I was interested that the extent of the break required a surgical intervention to literally hold his arm together. Feelings of guilt and inadequacy were very potent for the staff team as a result of this injury and the staff groups became a useful space for the staff to explore their feelings arising from this. I was also aware of my own feelings of inadequacy that were activated by this and of a temporary loss of faith in my work and this research. Supervision provided a useful forum to reflect upon my feelings about Derek's injury and to make sense of it in the context of this research study.

Following this significant episode, I was interested in whether it might be possible for Derek to develop a less punishing sense of himself. In other words, if he tripped up on a guitar string, would he be able to recover from this and find a way to continue, so that the interruption became a small hiatus rather than a complete rupture? This chimed with some of Derek's descriptions in the SSIs when he spoke of being told by the staff team that he could not do or have something that he wanted. Was it possible for him to recover from this without first responding by self-harming?

5.4.6 Phase three: towards greater musical freedom

When Derek started bringing his guitar to sessions and told me how he liked to play his guitar in his bedroom, I asked him whether he had ever composed any of his own music or songs. He had not tried this, but seemed interested in the idea. He said he liked to play music for his mother but did not really know how to do it. We thought about whether this might be something he wanted to try out in music therapy. Although he was keen, I sensed some resistance to actually composing something that we might repeat, learn or even record, as opposed to an improvised piece which would change and evolve with each repetition and could not be pinned down. We were still at the stage where his music had to be *'right'* and, whenever he tried to play some music for his mother, if he felt he made a mistake or got the music wrong, it felt unbearable for him. We continued improvising, Derek on his guitar and me playing the keyboard. Derek only plays open strings so I had tried to tailor my music to the tonality of his open strings, playing chords that would fit with Derek's music. It occurred to me that I was doing exactly what he had been doing: in other words, searching for the right sound that would fit in with his music. I was surprised to realise the unconscious way in which I had also been drawn into Derek's search for the right sound. At this point I became curious about what might happen if I played some music that might not necessarily harmonically fit with his music. I wanted to see if Derek could tolerate tiny moments of a musical misfit or a misattunement and then recover from them. I was interested in whether or not it made a difference to his capacity to survive such moments, if I, rather than he, had been the one to introduce them.

We experimented with this over a period of weeks. I was thinking about Winnicott's concept of the 'good-enough mother' described in §3.7.4 and I was interested in whether Derek could tolerate me adapting 'less and less completely' (Winnicott, 1971, p.14) to his music in order that he might be able to develop a less self-punishing view of what he perceived as his musical mistakes. Initially, when I started to attune less to Derek's guitar playing, he looked confused and often he would adjust the speed or the rhythm of his playing to compensate for this misattunement. We were able to think about what these moments felt like and he spoke of not *'being together'* or the sound

not being '*good'*. Once he described feeling that I was not understanding him. It was clear that Derek experienced any misattunements as a painful disconnection between us. This allowed for some thinking about how we might recover from this. We began to literally play with this idea, in other words, trying out ways of playing where we might consciously misattune and then, quickly at first, reattune. A few weeks later, we were improvising, Derek on guitar and me on keyboard, and Derek caught his finger on a guitar string and stopped playing. I continued to hold the chord I had been playing; the music faltered for a second, but then Derek was able to continue. This was a hugely significant moment for Derek and the first thing he said after we had finished playing was: '*I carried on that time. Didn't stop.'* We were able to acknowledge the importance for him of being able to recover when something does not quite go to plan. He left the session and told his carer about this with great enthusiasm. In the final SSI Derek was able to tell me that, instead of self-harming when he felt angry, he would talk to the staff more. There seemed to be a parallel in both his music and how he managed his emotional life: in both he seemed more able to recover when something went wrong.

5.4.7 Composition

This shift in Derek's guitar playing that saw him increasingly able to survive small hiatuses in the music seemed to give him the confidence to return to the idea of composing a piece of music for his mother. He was able to articulate his ideas about how he wanted the music to be, what instruments we should play, the dynamics and tempo of the music and how long it should be. We were able to try things out and work collaboratively. I was struck by how any judgements about the composition were completely absent. Derek was able to say what he liked and did not like without couching it in the pejorative language of right and wrong. It was interesting to see how much more confident and less self-punishing he had become. We worked on the piece over several weeks, writing things down so we could re-create the piece and add to it week by week. When Derek decided he was ready, we played and recorded it in the session. It began with the organ voice on the keyboard, but not in the cacophonous way of his earlier music. It was a simple, elegiac melody which he wanted to play alone before I joined in with a simple piano ostinato. The music then became much more

vivacious and rhythmic as Derek changed to his guitar and established a new musical idea. Derek stayed on the guitar but gradually slowed down the tempo and developed a much more reflective and sad mood. Once the music ended there was a silence, after which Derek said: '*And that was for my mum, that was. It was good.'*

5.4.8 Summary of the three phases of Derek's music

Derek's music changed significantly over the year that he was part of this study. In the opening phase, Derek's music was characterised by huge, overpowering sounds. These seemed to match his overwhelming feelings about his mother's death which found non-musical expression through regular self-harming and the destruction of other objects. In the second phase, Derek was beginning to trust the music therapy space, to bring objects in and out of it, including his guitar. Ideas of identify were explored: being admired by an audience, feelings of self-worth and the role self-harm played in making him feel important and special. We experimented with the idea of recovery both in and out of the music. This extended to the musical recovery already described and also the idea of his physical recovery: allowing his wounds to heal when he had self-harmed and finding other, less destructive ways of expressing difficult emotions. The final phase of Derek's music seemed to be about exploring Derek's creativity, developing freedom in his musical expression and finding new ways of recovering from moments of misattunement.

5.5 The staff groups

The monthly staff groups, facilitated by my art therapy colleague, were attended by a core group of four members of staff plus two staff members who left during the group and two new members of staff who joined part way through. I will briefly introduce each member of the group. All names have been changed in accordance with data protection and confidentiality.

Shirley: Joint leader of the Juniper Close staff team. Shirley had a lot to say and often dominated the conversation, sometimes to the exclusion of others. She could often

meander on to different topics from the one in hand and her views went largely unchallenged by others in the group, at least in the beginning of the work. Shirley took on much of the stress and pressure of the house and could be very anxious. She was also warm, likeable and funny. Outside of work she was very good friends with Emily, the other team leader.

Emily: Joint leader of Juniper Close staff team. She was thoughtful and reflective in her interactions and was calm and kind. When Emily left the house to manage a more challenging house within the charity, her loss was seen to destabilise the house, particularly for Shirley who missed her support and friendship.

Des: Des was often seen as very jokey but sometimes with a slightly cruel edge. He made some very barbed remarks about Derek in the early groups and expressed some ambivalent feelings towards him. He seemed to enjoy the challenge of working with Derek and it appeared that he often wanted to outwit him. As time went on, Des was able to show some much warmer feelings towards Derek and they found ways of enjoying each other's company. Des often found it easy to distract Derek when he sensed him becoming negative in his thinking or sensed an episode of self-harm might be imminent. He was also perhaps seen as a bit of a maverick among the staff: he would often deviate slightly from the agreed staff boundaries to give Derek his cigarette early or give him an extra snack before dinner. Des also made remarks about wanting his own therapy and seemed to envy Derek's access to music therapy.

Peter: Peter was considered a senior member of staff. He had worked at Juniper Close for a number of years and knew Derek well. He was able to stick to the agreed boundaries and guidelines for responding to Derek but did so without any particular warmth towards him. He often spoke about looking for another job. He expressed the view that Derek was unlikely to change.

Trisha: Trisha was a very quiet member of the group who seldom spoke, apart from when the group was quiet. She brought some warm insights to her work with Derek. She was often rather moved by him and was gentle and sensitive.

Craig: Craig was a new member of staff and left after six months. He was very thoughtful and offered a positive and more hopeful view of Derek. He clearly enjoyed Derek's company and was curious about him.

Miranda: Miranda joined the group at the end of the first six months. She was very calm and thoughtful and could manage difficult situations with confidence. She seemed to quickly gain the respect of the other staff. She was able to adhere to the staff guidelines about managing difficult situations with Derek but could do so with warmth and thought.

Jane: Jane joined the staff team at the end of this study. She was transferred from another home within the charity. The staff seemed to find her difficult to fathom and she did not seem to be particularly liked by the rest of the group. She only attended the final few groups.

5.5.1 Group interactions

As a group, the staff team were lively and chatty and enjoyed acting out scenes of daily life from within Juniper Close. Dark humour was injected into a lot of the conversation and this seemed in part to be a way of holding at bay much deeper anxieties and more ambivalent feelings towards Derek and also each other. The group had very high expectations of themselves and also of Derek and the sense was very much that things had to be perfect or else they were not good enough. They found it difficult to hold on to good things so that, even if they had had a good day with Derek, they would focus on a small thing that had not quite gone to plan. It quickly became clear who the more dominant members of the staff team were and their voices and opinions tended to prevail. The group found it difficult to reflect and often used humour to divert away from thinking about potentially difficult feelings and situations.

In both the SSIs and the monthly groups they wanted the SGF and me to know that they always did their best and did everything asked of them from the management team above them. They spoke of '*jumping through hoops*' and following guidelines to the

letter. It was only very close to the end of the monthly groups that the staff were able to acknowledge that this was not always the case and in particular that certain staff members deviated significantly from this.

5.5.2 The staff groups: first six months — coercion and trickery

One of the first themes to emerge in the staff groups was, in the words of the staff team, *'coercion'* and *'trickery'*. They expressed the worry that, if staff tried to persuade Derek to do something that he was reluctant to do, it would precipitate an episode of self-harm. This would then lead to associated feelings of guilt that somehow the staff had *'made'* him do this. Although the staff team were sometimes very anxious about being seen to coerce Derek into doing anything he did not want to do, at other times they could be quite blatant in describing the ways in which they tricked or bribed him into doing things. An example of this came at the start of the music therapy work. Initially Derek engaged well. The staff team alerted me to a familiar pattern in which Derek would often engage with a new person, activity or treatment but then after a few weeks he would withdraw. This was indeed the case with music therapy and, after the first month, Derek repeatedly told the staff that he did not want to attend. The staff encouraged Derek to take responsibility for his decision by coming up to the department and telling me that he did not want to see me that day. By the time he had come to the department and seen me, he was often quite willing to come to his session. However on other occasions it was clear that the staff were saying to Derek that if he came to music therapy he could then go out for cake afterwards. Already the staff were exploring the idea of how to get what they want as well as the ways in which they felt Derek manipulated them to get what he wanted. By agreeing to participate in this research study they were able to bypass the ordinary team waiting list to access music therapy for Derek more quickly. This was because I had some designated research time within my clinical post to see service-users for this PhD study. The SGF and I wondered if, initially, the staff team felt tricked into attending the staff group (even though they freely consented to it) in order to ensure Derek could access music therapy.

The issue of boundaries permeated the staff groups but particularly so in the first six months.

5.5.3 The staff groups: the second six months — a shift in thinking

During the second six months of the group there was a significant reduction in Derek's self-harming. The staff reported no incidences of self-harm in the month before the final SSI, compared to seven or eight incidences in the month preceding the first SSI. Even though the staff team could acknowledge that this represented significant progress, they quickly shifted their focus to other difficulties they perceived in Derek such as his negativity towards others. It felt very difficult for staff to be able to hold on to positive developments. It is interesting how the staff team and Derek seemed to mirror each other in finding it difficult to hold on to what had been positive. They both seemed to need to sabotage and marginalise whatever had gone well. Through the monthly staff groups, it became possible for the staff to think about Derek in new ways and by the end of the study there had been a noticeable increase in the warmth staff were able to express towards him.

5.5.4 Parallels between themes emerging in Derek's music therapy and the staff groups

This section will consider some of the parallels that emerged between Derek's music therapy and the staff groups; it also considers the possible roles that Derek's self-harming might have provided for both him and also the staff team. Although the staff team at Juniper Close strove to give Derek opportunities to be independent and autonomous, in many ways aspects of his life remained limited and fell under the control or management of other people. Living in a group home with other people and a staff team affords few opportunities for privacy and secrecy, so for Derek to be able to go to his room and self-harm in private offered something that was both under his sole control and that potentially offered some excitement and drama. This had some congruence with what was seen by the SGF in the staff groups and by myself in the semi-structured interviews. There was much discussion about the '*daily grind'*, as

described by one group member, of working at Juniper Close. The staff frequently spoke of feeling stuck; a sense of hopelessness and boredom pervaded particularly the early groups. As much as the staff complained about Derek's self-harm, they also described these occasions and the injuries Derek caused himself in great detail, sometimes slightly voyeuristically, and we began to glimpse a way into which Derek's self-harm also provided some excitement for the staff team. The staff described feeling undervalued; they needed to let us know how difficult their job was and how hard they tried to make life better for Derek. Here is an example from the transcripts of the semi-structured interviews with the staff team that demonstrates this:

'*I constantly run through my head thinking about other ways we can help him*.'

This need to be seen to be trying very hard to improve things for Derek might have been a way to deny some of the more ambivalent feelings they had about Derek. The staff team's feelings of boredom and hopelessness quickly emerged in the groups:

'*Derek's just Derek. Nothing changes*.'

'*You can virtually write Derek's day by what he's going to say. You can guess that at this time of day he's going to say that and he does*.'

There seemed to be a parallel here between how Derek described feeling and how the staff team experienced their working life. Common to both was a feeling of flatness, boredom, hopelessness and powerlessness. When Derek self-harmed, as much as the staff team appeared to find this difficult and distressing, responding to it conferred a sense of importance and value to them and to their work. For both Derek and the staff team, self-harm provided them with a sense of meaning, excitement and control, although on a conscious level the staff team certainly rejected this idea.

Another striking parallel was the way in which both Derek in the music therapy and the staff in the groups negotiated finding a way of being heard: Shirley, the manager of the staff team, quickly took on the role of the spokesperson for the group; she would often interrupt other people and would usually be the first person to speak. If another staff member was describing an aspect of Derek's behaviour, she would often add her own

interpretation of things. She would describe situations in which she was brought in because somebody else was unable manage the situation; she would also allude to being able to achieve better outcomes because she is on a higher level to the other staff:

'*He* [Derek] *accepts certain things from me more than others because he knows that I'm at a different level*.'

Inevitably this led to considerable resentment and splitting within the staff team, resulting in some staff members becoming angry and expressing hostility towards Derek. The following excerpt from the first SSI shows the extent to which the second staff member, Des, feels undermined by Shirley having to come in and encourage Derek to take his medication, something Des had been unable to persuade him to do. Whilst we might reasonably consider this to be an example of splitting within the staff team, it is clear that Des's anger is mainly towards Derek, who he perceives as having '*got him*' in some way, rather than with Shirley:

(S) '*I came in and got him to take his medication, fresh face, different thing*.
(D) *And I thought: "Right, Derek, you won't get me like that again*." '

The tendency for the staff to interrupt each other in the groups and the SSIs meant that it was common for several people to be speaking at once. This reminded me of the way Derek mapped several different voices on to the keyboard at once, with the result that it became difficult to hear the individual sounds. So it was in the staff groups: individual voices could easily become lost; quieter members of the group were overshadowed by the more outspoken ones. Sometimes it could be difficult to find a way to penetrate the group's talking to express a thought, clarify something or ask a question. In this way there were parallels between the group and Derek: both felt impenetrable in quite particular ways. Although impenetrable for different reasons, in both settings, the SGF and I had, at times, found it difficult to make a response.

5.6 Case study 2: Janet

Janet is a 63-year old woman with mild learning disabilities who lives independently in a small flat in a rural market town. She receives support from a care staff team who visit her three times a day to assist with personal care, shopping and domestic tasks. During this study, the staff team consisted of approximately six members of staff who supported Janet on a 1:1 basis according to a rota. Janet often did not know who was going to arrive to support her, but appeared to accept this and seemed happy for other people to make decisions about her care and how she was supported.

Janet has two older sisters, both of whom are married. Janet spoke to them on the telephone every day although these calls often lasted for only a few moments. Janet was rather ambivalent about her sisters: she was financially dependent on her sisters yet also frustrated by their involvement in her life. An example of this could be seen in how Janet came to acquire her clothes. One of her sisters chose clothes for her, bought them online and took them to her. Often they were the wrong size or Janet did not like the style or design; when this happened Janet did not tell her sister but put the clothes in a cupboard and did not wear them. The idea that Janet might have told her sister or indeed bought her own clothes was quite a challenging thought for her when I first met her. There were ways in which she appeared to prefer to remain helpless and dependent upon others despite the fact that she would always refer to how much she could do for herself and how important her independence was.

5.6.1 Janet and self-harm

The nature of Janet's self-harming was complicated and felt particularly challenging to her staff team. Janet had very ulcerated legs with extremely poor skin integrity. One leg was significantly worse than the other. I only knew her legs to be heavily bandaged or, at best, in a support stocking. Janet had regular episodes of urinary incontinence with the urine burning the skin, leading to open, weeping wounds. The skin then became very irritable and, when the staff were not there, Janet poked sharp objects down her bandages and scratched the wounds until they bled. Sometimes Janet would

then urinate further on to the bandages so that when staff arrived they felt presented with *'a mess'* (staff's words) to deal with.

5.6.2 Staff's understanding of Janet's self-harm

Janet's staff team found her self-harming very difficult to bear and in particular their own disgust and revulsion about the particular ways in which she self-harmed. As a result of the condition of Janet's legs, she made regular visits to the GP surgery, usually between two or three times a week. The staff at the surgery knew Janet very well and told her about their families and their lives outside of work. For Janet, the practice staff occupied a confusing role: Janet considered them her friends because she asked about them and their families and remembered the details of their lives away from work. On some level they asked about Janet too but, as her staff team tried to point out, they were not calling in to visit Janet or taking her out for the day. However, these visits to the surgery were an integral part of Janet's week: whilst she appeared to express frustration that her legs were not getting better, the staff felt that what they saw as her deliberate urinary incontinence maintained both the ulcerated state of her legs and therefore these 'social' visits to the surgery.

Certainly Janet's life could be seen as rather empty. She lived in a very small and dark flat and essentially stayed in one room, sleeping in her chair rather than in bed. Janet found her learning disability hard to accept and did not readily associate with other people except her staff team and health professionals. Although staff tried to introduce Janet to other people they support, she never wished to pursue any friendships, preferring to be alone in her flat. When the staff were not there, Janet would watch television (police and emergency service programmes being amongst her preferences) or else try to make the time pass more quickly by putting a blanket over her head and either sleeping or sitting alone in the dark. In spite of Janet's obvious fondness for the staff, when it was time for them to leave, she could only manage this by a pseudo-angry exchange with them. For example she may have told them:

'*Bugger off, go on, hop it, you useless waste of space*.'

This was accepted as a jokey exchange between Janet and the staff team and they seemed to understand this as a form of teasing, but it can potentially be thought about in various ways. It could he heard as an expression of how Janet felt about herself. In the second SSIs staff member Delia said this:

'*Once, she even said to me, after I'd changed a wet bandage: "Delia, I'm just completely useless and stupid" and I said: "No, Janet, no you're not. You mustn't say that about yourself." It broke my heart*.'

Equally, telling the staff to *'bugger off'* could belie a much more painful fear of abandonment. Janet struggled deeply with loneliness and being alone. Her urinary incontinence, which staff believed to be conscious and deliberate, only occurred when Janet was by herself. When she was out of her home it did not happen. The fact that Janet appeared to have some physiological control over her bladder made her episodes of urinary incontinence feel like a deliberate attack on the staff and it was difficult for them to think about why Janet appeared to need to sabotage their efforts to care for her leg and offer her what they considered to be a better quality of life. The staff spoke of the efforts they went to in changing Janet's bandages and providing the best care they could and then expressed their exasperation and anger towards her when, just as her leg improved, Janet was incontinent and her skin integrity broke down again. Everyone was caught up in this cycle: for Janet, if her legs were to get better, she would lose the lifestyle and visits to the surgery that having ulcerated legs afforded her; for the staff, they felt they did everything to care for Janet's legs and provided opportunities for her to have days out and Janet then sabotaged this at the last minute. Everyone was frustrated and upset and nobody had what they wanted.

5.7 Introducing Janet's staff team

Janet had a staff team that visited her for a number of hours across each day and evening. She also had periods of time when she was by herself. Janet's care was provided by an agency and she had a core staff team of six people. Some of the staff members had known Janet for many years, even supporting her in previous accommodation, meaning they may have known her for fifteen years or more. It was a

well established team of community support workers that supported a number of people living in the community, of whom Janet was one. This meant that each member of the staff team had a number of people to visit and assist in the community on any given day. Each visit had an approximate allocation of time, and staff had a sense of what needed to be accomplished at each community visit, centred around the needs of the individual service-users. It was clear that the staff team found this way of working very demanding: a delay during one visit had an impact on the rest of their day, meaning the staff ran late for other support visits and frequently worked beyond their contracted hours. In the SSIs staff spoke regularly about the impact of their work on their home life and the guilt they often felt about not being available to their own families because of work pressures. It emerged in the monthly groups with the SGF that staff used their own personal mobile phones for work purposes and regularly received calls about service-users in the evenings, weekends, days off and even when on holiday:

'*And we'll still get texts throughout the evening, won't we? Until about 9 o'clock at night with different messages about the next day*.'

The demands of the work meant that the team manager had not been able to offer any individual supervisions or staff meetings for several months because of time pressures. This meant that staff members were feeling isolated and described 'passing in the street':

'*We don't really get the opportunity to be in a group like this, do we?*
We're normally in and out and passing in the street, not even staff meetings…
There could be a month where you don't really see anyone.'

Morale was clearly low in this staff team and, although a core number of staff remained committed to the group, it was much more difficult for this staff team to prioritise attending the monthly staff groups. The demands of the work had also helped to define a view expressed by some members of the staff team that it was better not to think about things too deeply and simply get on with the work:

'*Sometimes it's best not to think too much about how it makes you feel and just get on with the job*.'

By the end of the study, there was a sense that the staff team had found the monthly groups helpful as well as challenging. In the final SSI the staff acknowledged the importance of finding ways of being together and appreciated the ways in which the monthly groups had helped them to feel supported and better understood. They were creative in thinking about how they might take this forward outside of this research study.

5.8 Janet's music

When I first began seeing Janet for music therapy she was very resistant to thinking about her self-harming. Locating it firmly in the past as something she used to do but no longer engaged in, I was mindful of how defended Janet was against thinking about any areas of her life that felt difficult. She spoke very much in terms of bright colours: she liked to dye her hair a very vivid shade of orange; she had bought a bright orange car and a yellow mobile phone; conversation was always upbeat and jocular. If I suggested that something might be painful or difficult, she would quickly dismiss it, often saying that it did not matter, or it was OK really.

Janet was interested in the instruments: she was drawn to instruments that were shiny or playful, in particular a small wooden guiro in the shape of a frog. She also used her voice. She would pick up the frog guiro and run the small wooden beater over the grooves on the back of the frog. This produced a scratchy wooden sound. She would begin this slowly, gradually getting faster and screwing her face up as if expressing pain. I was struck by how itchy and intense the sound was and I was aware of a strong impulse to scratch my own skin. At a time when Janet's self-harming could not be expressed in words, she had found, through music, a powerful way of communicating something of her experience of having itchy, irritated and inflamed skin.

Janet also used her voice in a very striking way: vocal fry is a method of using the voice to produce a low, guttural, creaking, croaky sound. Sharing certain properties of Janet's guiro playing, her vocal sounds were also scratchy and wiry in quality. She did not vary the pitch of the sound, so, like the guiro playing, it felt very percussive. I was mindful

of the absence of a melodic element to Janet's playing and experimented by providing this in my own playing. I also used my voice to try to engage Janet in a vocal dialogue but, throughout the year of music therapy, Janet did not develop this aspect of her music-making.

5.8.1 Intensity and duration of Janet's music

During these early improvisations Janet's music often lasted for under a minute. I was reminded of telephone calls Janet described making to her sisters: regular, frequent but very short. It felt very difficult to sustain things with Janet, both verbally or musically. Interactions were brief, sometimes intense and then fell away, often into an awkward silence which Janet would break by something seemingly more prosaic, such as telling me about her shopping list or domestic chores that needed attending to. The nature of these short bursts of intense playing felt like itches: they needed to be urgently addressed (through the playing of energetic music) and then temporary respite could be found. I was interested in whether it was possible to find a less intense but more sustained way of being together in the music.

5.8.2 Bass metallophone

Janet had often used the bass metallophone as a place to put her glasses, her identity badge (which she needed to access the building we worked in) or a glass of water. I was interested in the way she made the metallophone redundant as a potential for creative music-making by using it as a table. One week, I decided to arrange the room differently, bringing the metallophone and the keyboard into a more prominent position. Janet noticed immediately and challenged me about the change. Given the ways in which Janet had been happy to allow other people to make decisions for her, this seemed an important moment in our work together. I noticed that her reaction was similar to how she dismissed the staff when it was time for them to leave: it was a mixture of pseudo-teasing and mild insults and seemed designed to leave me feeling stupid:

'*What are you doing, you silly sod? Have you lost your marbles? The room is all different. Have you forgotten what you're doing?*'

This was expressed with Janet's characteristic laughter and jocular manner, but actually felt anything but jolly or friendly. The implication that I might have lost my mind made me wonder both about Janet's mind and what she might have lost. I also wondered what might emerge if she really allowed herself to 'let go' of the jocular manner and laughter. I suspected she was in a rage. The idea that I had forgotten what I was doing made me wonder if Janet thought I had forgotten how to look after her properly. I thought she seemed angry and I suggested this to her. She neither agreed with or denied this. Instead she picked up some bongo drums and began banging them with her fists. Quickly she discarded them, grabbing the beaters to the metallophone and playing in a loud, seemingly random way. I was at the keyboard trying to frame Janet's playing with chords that were tonally ambivalent but not discordant. Janet was watching me with great intensity and the music settled into a pattern of her playing two notes together on the metallophone loudly, waiting for me to respond on the keyboard and then playing again. It was a very powerful exchange and it felt like Janet was squaring up to me in the music. She seemed strong and defiant. It was our longest co-improvisation and lasted around seven minutes. A long silence followed it, after which Janet said: *'That feels better.'* I felt that Janet was shocked by what had emerged in her playing. She seemed shaken and we were able to think about some of the ways in which she was angry about her life and her circumstances. The next week, Janet did not attend. When I rang the staff, they explained that Janet's leg had *'broken out',* necessitating a stay in respite care. When Janet's skin integrity broke down to a sufficient extent that she required antibiotics four times daily, she had to attend a respite care facility as it was beyond the scope of the community staff team to manage this level of medication. It was perhaps unsurprising that Janet had not been able to attend after what had happened the week before. I sensed that it had been disturbing for her to be in touch with such powerful feelings and I wondered if, unconsciously, she had needed to get herself to somewhere where she would not have to be alone and could be looked after in a full-time way.

5.8.3 A new way of playing

When Janet returned from respite care, she told me, with great enthusiasm, how much she had enjoyed it. The next three months saw several breakdowns in skin integrity and readmissions to the respite facility. Janet became more able to speak about her feelings and developed new insights into the links between her incontinence and her loneliness. She could tolerate the idea that urinating on to her legs and the resulting breakdown in skin integrity became a way to escape her flat and her loneliness. This allowed her to explore whether she might actually want to live in a different way. She began to formulate ideas about where she might wish to live in the future and what she could tolerate in terms of living with other people. These ideas were discussed with her staff team and, by the time this research project had finished, a care manager and Janet's staff team were discussing future accommodation options for Janet.

Janet's music also underwent some significant changes: co-improvisations became longer and more sustained. Janet became interested in some of the melodic instruments and was able to produce some very poignant, spacious melodies, very different from the earlier, more frenetic 'scratching' sounds on the guiro. The music gave Janet a means to convey her sadness and her rage. In the SSIs for the staff teams, several members of staff remarked upon Janet's capacity for empathy, something they had not seen before. They felt that she had become emotionally broader and I wondered if this was because she had been able to find new ways to be expressive and to encounter her emotional self.

5.9 Janet's staff group

The monthly staff groups, facilitated by my music therapy colleague and SGF, were attended by a core group of five members of staff. During the year there were some small changes of personnel with two staff members who left during the group and one new member of staff who joined part way through. I will briefly introduce each member of the group. All names have been changed in accordance with data protection and confidentiality.

Anna: Team leader for the community support team, Anna had known Janet for many years. She was extremely loyal towards and protective of her staff team, often referring to them as *'my girls'*. She saw little possibility of hope or change for Janet and in the first SSI expressed the thought that Janet would remain as she is for the remainder of her life. Anna was warm, realistic, over-worked and stressed. Anna attended the first of the three SSIs but was not able to commit to the monthly staff groups due to time pressures.

Lou: Lou was a care worker in her late fifties who has also worked with Janet for many years. Outspoken and honest, Lou did not shy away from expressing both her repulsion for Janet's self-harming and also her fondness for Janet. She had very strong emotional reactions to Janet and had a lot to say in the monthly staff groups.

Gina: Gina was the youngest of Janet's carers and the least experienced. Other staff described her as having a personality clash with Janet and, part way through this work, Gina was removed from Janet's care staff team after Janet complained about her. Despite efforts to keep Gina both on Janet's care staff team and in the monthly groups, this was not possible.

Delia: Delia and her daughter Tori were both members of Janet's staff team. Delia was very affected by Janet's self-harming, often taking this very personally and feeling that she had failed Janet.

Tori: Tori brought a determination to do her best for Janet to her work. Although one of the younger members of the team, she brought both insight and practicality to her work.

Dee: Dee was a much quieter member of the group. She seemed less personally affected by Janet's self-harming and was able to respond to it in a less emotional way than other members of the staff team.

Marina: Marina was another younger member of the team. Warm, compassionate and insightful, Marina was open to thinking about Janet in new ways and often helped the rest of the staff team to find different ways of understanding Janet.

Sally: Sally joined the team during the last three months of the research study. She got to know Janet well in this time and seemed to have a fresh view of her that was less encumbered by a sense of hopelessness.

5.9.1 Staff group interactions

When I met with the staff team for the first SSI, I was struck by how loud and lively they were as a group. There was lots of teasing, laughter and banter; there were doughnuts, cakes and tea and what appeared to be lots of goodwill and kindness. Quite soon, a different sense of things emerged: the staff were extremely stressed; ambivalence about the work was expressed; they needed me to understand how hard they worked and in what extreme circumstances; they felt utterly hopeless about Janet's self-harming and had little, if any, expectation of change.

5.9.2 The first six months

The first six months of the monthly staff groups were characterised by a sense of hopelessness about Janet's self-harming. Staff were very graphic in their descriptions of her self-harming, projecting on to the SGF (and me in the SSIs) their repulsion when Janet was incontinent. Any sense of progress or success was immediately negated by something that had not gone so well. Although the staff were able to voice their disgust at Janet's wounds, it was much more difficult for them to think about how they might own their more ambivalent feelings and integrate them into their idea of what constituted a good carer. The staff team struggled to understand what they perceived as Janet sabotaging their efforts to provide her with good experiences and days out which were thwarted when Janet was incontinent and needed to have her dressings attended to at the surgery. It was very difficult for the staff to reconcile what they felt was Janet's desire to have days out with what also appeared to be a conscious act of urinary

incontinence. It seemed nonsensical to them that Janet might attack the very thing that they felt she wanted.

5.9.3 The second six months

During the second six months, Janet's self-harming became significantly worse, necessitating many admissions to respite care. Later in this period, things improved to the point that, by the end of the research study, Janet's legs had healed completely and she was out of bandages. This second period of six months therefore saw a huge amount of change both in terms of Janet's self-harming and the prospect of different accommodation for Janet. Conversations about accommodation began six months into the study and continued throughout the second six months. As one staff member said in the second SSI:

'*Yeah, I think six months ago, before Janet started seeing you for music therapy, these conversations just wouldn't have happened. Janet wouldn't have been able to talk about being lonely and we wouldn't have necessarily linked wetting herself with all the stuff we've talked about*.'

The SGF was very struck by how hard it was for the group to hold on to any sense of progress, especially in terms of Janet's legs getting better. Pens and paper were used in these groups in response to the SGF's recognition of the difficulties this group found in talking about the feelings they had about supporting Janet. Thoughts that were difficult to verbally acknowledge or articulate, could be written down and shared in a way that perhaps felt less direct. Relief was expressed when many of the group members had shared similar feelings.

Janet's staff team found it very difficult to acknowledge any differences between themselves or to acknowledge any splits or rivalries, common to many teams that work together in this way. They felt that a well functioning team was linked to all its members thinking and feeling the same and we were aware of how difficult it was for them to explore any areas of divergence.

Of particular significance in the second six months of this work was the staff team's capacity to begin thinking about why Janet might appear to sabotage a planned trip out by being incontinent. This had been unavailable to think about in the first six months, but as the group came to a more compassionate way of thinking about Janet they were able to make room for the idea that she might experience social anxiety and may be rather fearful about going out. This allowed them to experience her incontinence in a far less personal way.

5.9.4 Parallels between themes emerging in Janet's music therapy and the staff groups

I was very struck by the way in which both Janet and the staff team needed to present a very sunny, optimistic sense of themselves: for Janet it was the orange hair and car, yellow mobile phone, lots of sweet, indulgent food and a sense that everything was fine; for the staff team it was doughnuts, teasing, camaraderie and humour. Both found it difficult to face the reality of their situations. Janet, although living more independently than Derek, still had limited opportunities for choice and control in her life. She was subject to the comings and goings of staff, never quite sure who was going to arrive and was dependent on staff for aspects of her personal care and domestic help.

Both Janet and the staff team expressed some very ambivalent feelings about each other: the staff team expressed a great deal of warmth and fondness for her, but also repulsion and frustration; Janet clearly liked her staff team a great deal, but also could recognise their frustration with her and found this hard to bear. She also described some of the decisions they made about her care *'stupid'*.

5.10 Summary

Through these case studies, this chapter has illustrated the processes through which the data was generated for this research study. Presenting the two cases in turn, I have first introduced the participants, giving a brief history of their backgrounds and their clinical presentations, before briefly introducing their staff team. I have then given a

description of their music therapy sessions, relating this to their responses to the SSIs across the timescale of the study. A similar description of the staff groups followed, before parallels were drawn between what emerged in both the music therapy sessions and the staff team for each participant and their staff team.

The next chapter will present the results of the analysis, culminating in two master table of themes from the two participants and the two staff teams.

Chapter 6: Results

6.1 Introduction

In this chapter I will first present the results of the qualitative data which was gathered through the semi-structured interviews with the two service-users. This qualitative data, analysed within a framework of Interpretative Phenomenological Analysis, provides subjective data about the service-user's experience of self-harming. The results will show any correlation between the interventions of music therapy for the service-users and any reduction in the frequency of self-harming. The chapter will present the results from the two service-users, creating a master table of themes for each. There will then be a synthesis of the analyses of participant B (Derek) and participant F (Janet). This process will then be repeated for the two staff teams. I will explain the method for conducting this synthesis and show how the superordinate themes for both participants and staff teams were analysed for points of congruence and divergence. There will be a further discussion of these results in Chapter 7.

6.2 IPA of the semi-structured interviews for participant B: Derek

In this section the IPA analysis of the semi-structured interviews for participant B will be demonstrated by a table of the superordinate themes for the service-user and a separate table for the staff team.

6.2.1 Superordinate themes for participant B: Derek

Once the initial stages of the analysis had been completed according to the description given in §4.5.2, the following table of superordinate and cluster themes emerged. Themes in bold at the top represent the superordinate themes, the themes underneath are the cluster themes and the text on the right is an indicator from the transcript with a page and line reference.

Four superordinate themes emerged from the analysis of Derek's three SSIs: a destructive sense of self; a vulnerable sense of self; a self that cannot be understood or controlled; and a sense of hope.

Superordinate and cluster themes	Page/ line	Indicators from transcript
A destructive sense of self		
self-harm as frightening	8.11	'frightened me'
destructive self: self-harm as disabling	2.12	'can't use it (hand) yet'
loss of control: explosive, unpredictable feelings	4.17	'just came over me'
drama of self-harm	2.5	'went to hospital'
maintaining the injury	3.17	'if it goes red, I go back again'
lack of containment	4.17	'couldn't stop it…bleeding'
A vulnerable sense of self		
seeks reassurance	6.18	'pleased to see me, aren't you?'
elicits sympathy	2.9	'can't use hand'
grieving	3.5	'miss me mum'
feels worse after self-harming	7.6	'worse'
vulnerable	7.10	'shaking, nervous'
avoidance	13.5	'can't remember now'
uncertainty of role	5.18	'don't let me do it'
lack of power	5.8	'mustn't stand on the settee'
A self that cannot be understood or controlled		
awareness of impact of self-harm on others	9.5	'he was upset about my hand'
responsibility of self vs blaming others	5.4	'she made me do it'
struggles to accept boundaries from staff	5.9	'she told me to get off'
struggles to acknowledge self-harming	12.15	'stopped doing that'
denial of original self	13.3	'don't do it'
A sense of hope		
acknowledges practical help from staff	8.6	'put…those bandage things on'
acknowledges vulnerabilities	14.11	'ask staff to help me'
taking responsibility for owning anger	13.8	'still get angry'
sees staff as potential helpers	10.8	'she did help me'
can acknowledge frustration and self-harm	13.10	'tell someone when I'm angry'
development of insight	16.9	'did it because I was angry'
impact of music therapy	18.7	'helps me to come here'

Tab. 6.1: Table of superordinate themes for participant B

6.3 IPA of the semi-structured interviews for participant F: Janet

This section summarises the results of the IPA for the second case study, participant F, whom I have called Janet. The table below shows the superordinate themes (in bold) with the cluster themes underneath and an indicator from the transcript on the right.

6.3.1 Superordinate themes for participant F: Janet

Four superordinate themes emerged from the analysis of Janet's three SSIs: an unwanted self; an important self that impacts upon others; a staff team that Janet felt were ambivalent; and a self that can look forward.

Superordinate and cluster themes	Page/ line	Indicators from transcript
An unwanted self		
defensive	1.9	'I haven't done it at all' (shifts uncomfortably)
denial of self-harm	1.10	'I've stopped doing that altogether'
wants to disappear	36.3	'I put my blanket right over my head'
feelings of shame	22.6	'I feel a bit ashamed of myself sometimes'
frustration with self	3.17	'I'm fed up with doing it (self-harming)…'
feelings of uselessness	34.9	'I'm useless, it'd be better if I wasn't here.'
An important self that impacts upon others		
keeping busy: sense of importance	20.5	'…got to go shopping then go to the clinic…'
making herself memorable to others	6.8	'I'm cheeky…I drive them scatty.'
sense of pride	17.18	'This morning there was no wee in my bandage'
social self	10.8	'I bump into people I know'
wanting to shock	42.2	'I've got a naughty DVD: shown my sister'
A staff team that Janet felt were ambivalent		
staff attend to practical things	2.18	'They change my bandages and ring the doctor'
staff show J when they are frustrated	22.15	'I think they get frustrated'
J can tell when staff are frustrated	24.2	'I can tell by their faces sometimes'
staff can be punitive	26.6	'staff … get my breakfast out of the safe'
staff as concerned rather than frustrated	37.1	'I think they felt worried…'
A self that can look forward		
can admit to frustration	2.6	'Not very happy about doing it' (self-harming)
able to acknowledge self-harm	2.3	'It bleeds…bandages are covered in blood'
can talk about painful things	33.20	'it's horrible…it gives me the creeps'
music therapy as helpful	26.16	'it helps me to get all the stress out'
looking forward	32.16	'there's a new shop. Have to go for look round'
feels happier	29.9	'(MT) made me feel much happier in myself'
positive body image	37.17	'I've lost some weight…helped to give me some confidence back. And coming to MT'
taking responsibility	28.15	(sitting with legs up) 'It helps the fluid go up my legs'
interested in sex	41.5	J: 'Fifty Shades of Grey R: Ah, all about sex J: Yeah….I've watched it several times'

Tab. 6.2: Table of superordinate themes for participant F

6.4 Conducting the synthesis

The superordinate themes from participant B were used as a starting point to begin the synthesis. Large sheets of paper contained a list of the superordinate themes from participants B and F. Beginning with participant B's superordinate themes, areas of congruence and divergence within participant F's transcript were identified. Themes were selected not only for their prevalence but also because of the way they may highlight other themes within the analyses.

6.5 Master table of themes for participants B and F

The table below shows the superordinate themes that have emerged as a result of synthesising the superordinate themes from each individual participant. Some decisions were required about which themes to prioritise; these were determined by a combination of prevalence within the transcript and the significance of the theme in relation to the research questions. These were then distilled into this final master table of themes.

The two participants were invited to think about the impact of self-harming on their lives. During the SSIs, questions were asked about the methods by which the participants self-harmed, the frequency of self-harming and how they felt afterwards. The focus then turned to the staff and whether the participants had found their responses helpful. Finally they were asked whether or not they had found having music therapy helpful.

The accounts given by Derek and Janet generated the following four superordinate themes: an uncontained self; how the staff teams were experienced; an unwanted self; and positive changes. Within each of these themes there were degrees of congruence and divergence in how the two participants expressed the superordinate themes.

Superordinate and cluster themes	Page/ line	Page/ line
An uncontained self	**Derek**	**Janet**
a lack of control	4.17	30.19
a lack of containment	8.9	18.12
maintaining injuries	3.17	21.15
drama of self-harming	2.5	2.3
aware of impact of self-harming on others	9.5	22.15
How the staff teams were experienced		
staff attend to the practicalities of self-injury	8.6	2.18
staff can be experienced as punitive	5.19	26.6
An unwanted self		
feeling vulnerable	7.10	21.7
avoidant/wanting to disappear	13.5	36.3
denial of self-harming	13.3	1.10
feelings of shame	7.6	22.6
feeling powerless	5.8	3.16
denial of self	13.3	1.9
Positive changes		
reduction in self-harming	15.19	30.1
taking responsibility	13.8	28.15
can acknowledge frustration and self-harm	13.10	2.6
development of insight	16.9	41.2
positive impact of music therapy	18.7	26.16

Tab. 6.3: Master table of superordinate themes for participants B and F

6.5.1 An uncontained self

This was a rich theme for both participants. Each of them reported that their self-harming felt uncontrollable and compelling. Their life circumstances meant that frustration and boredom could reach such an extent that self-harm offered a way to ameliorate these unwanted feelings. There was a divergence in the reasons why each participant self-harmed: Derek often experienced angry, explosive feelings that came over him suddenly; Janet experienced feelings of chronic emptiness and loneliness. For both there was a congruence in the spilling out of bodily fluid that could not be contained when they had self-harmed. Derek's account uses quite graphic, dramatic language to describe the bleeding from an injury he caused to his hand:

D: '*And it's all running down here. Couldn't stop it. All bleeding. Couldn't stop it.*'

His account captures a lack of containment in quite a literal way: the blood could not be stopped; he expressed this in a breathless way with a quick delivery that conveyed something of the drama and urgency, but also the possible excitement that he felt at seeing what he had done.

Janet's descriptions were less emotionally heightened and told of her urinary incontinence, which both Janet and the staff believed was under Janet's control. Janet would describe being distracted or forgetting that she might need to use the toilet:

J: '*They were dry* [bandages]*, then they were wet…*
Int: *OK…so what do you think happened between waking up and realising your bandages were wet*?
J: *I don't know, I think I just forgot to go to the loo…I was watching telly, that's mostly my trouble*.'

Janet's use of the word 'trouble' might suggest that she recognises her urinary incontinence and her capacity to become distracted as a problem (possibly more for her staff team than for herself). Like Derek, Janet expresses the aspect of uncontained bodily fluid with a sense of urgency:

J: '*They* [staff] *take them off straight away. They come off straight away when they're wet. Like if they're leaking they come straight off…*'

Descriptions like *'straight off', 'straight away', 'leaking', 'all running down', 'couldn't stop it'* and *'all bleeding'* are graphic, suggesting a sense of something that is unconfined and unstoppable, needing attending to with urgency.

A further congruence lay in aspects of their family life: both had very little contact with family and felt lonely and unattended to. They each wanted people to be interested and curious about them, beyond simply attending to their physical needs. It is notable that both Derek and Janet self-harmed in ways that required their staff teams to spend additional time with them, meaning that there could be an impact on the home lives of the care staff, who often had to work beyond their contracted hours. Both staff teams spoke of the additional time that had to be given to Derek and Janet because of the nature of how they self-harmed.

The two participants were aware of the impact of their self-harming on others. Janet recognised that staff were frustrated with her when she self-harmed:

Int.: '*And how do you think the staff feel*?
J: *I think they get a bit frustrated. I think they get frustrated. Yeah*.
Int.: *What makes you think they get frustrated*?
J: *I don't know what it is. I think they get fed up as well.*'

By saying that she did not know what it was, I wondered if Janet was finding it hard to think about the staff being frustrated with her. It was clear from the transcripts that Janet and Derek were both fond of, as well as dependent upon, their staff teams. Both found it difficult to acknowledge their need of the staff. For Janet, in particular, it was very difficult for her to think about the staff being upset or frustrated with her and sometimes she would say that she *'didn't know what it is'* if it was simply too unbearable to think about. For Derek, he was aware that one of the other men he lived with found his self-harming very distressing:

D: '*He was upset about my hand. He started crying*.'

I was aware from what Derek had talked about in music therapy that the two men did not get on and regularly looked for ways to upset each other. There was a divergence here between Janet's sense of how her self-harming impacted upon her staff team and Derek's sense of how his self-harming impacted upon his fellow tenant: Janet found it difficult to bear her staff team's frustration whereas, for Derek, I sensed from his tone of voice and the context that it made him feel quite powerful that he could have this much effect on another person.

6.5.2 How the staff teams were experienced

Derek and Janet each made reference, more than once, to the staff team reliably helping them in practical ways when they had self-harmed. This was a point of congruence and both participants were able to describe in detail the procedures undertaken by their respective staff teams in order to attend to any injuries. It was clear that both staff teams had procedures to follow in terms of wound management and both participants experienced being well cared for in practical ways.

Janet was also able to respond to this question on a different, other level: she was able to think about her staff team's emotional response to her when she self-harmed. The analysis of Janet's staff team revealed that they were very open in expressing their revulsion and disappointment when Janet had self-harmed. This would have been very clear to Janet. In the first SSI, when I asked her what the staff did when she self-harmed, she gave this reply:

'*They change my bandages and ring the doctor's to get an appointment. They help me, but they get upset when my leg's bad.*'

I was not clear what Janet meant by the use of the word *'upset'* and at that stage she was not able to say more than that. It seemed that Janet could recognise that the staff were unhappy in some way when she was either incontinent of urine or had poked a sharp implement down her bandages to make her leg bleed. In the second SSI, she could elaborate further on how she perceived the staff's emotional response to her self-harming and had told me that she thought the staff were frustrated and not very pleased:

Int.: '*So, can you tell me what makes you think the staff aren't very pleased?*
J: *I can tell by their faces sometimes…yes, it's their faces I can tell by*.
Int.: *And what can you tell by their faces?*
J: *The expressions on their faces as well*.
Int.: *Can you tell me what you think their expressions mean?*
J: *I think they're a bit fed up, that sort of thing, I'm sure they are*.
Int.: *What do you think they are fed up about?*
J: *Me*…'

Janet's tone of voice at this point in the transcript is rather quiet and sad. There is a contrast between the earlier excerpt and this one: previously she expressed uncertainty (or an inability to think) about why the staff might have felt frustrated, and here she articulates a more definite sense that the staff were fed up with her: *'I'm sure they are'*. By the end of the second SSI, Janet had elaborated further about ways in which she experienced the staff as punitive. Janet wears incontinence pads which her sister buys for her against Janet's wishes; she is very clear that she does not wish to wear them. In the transcript she stated very clearly that she did not like wearing them. Staff put them on, believing that the pads protected Janet's legs from her incontinence and a further breakdown of her skin integrity; as soon as the staff leave, Janet cuts them out with scissors. Whilst discussing whether or not Janet finds the staff team helpful when she has self-harmed, Janet began to describe ways in which she seemed to be experiencing the staff as punitive:

J: '*They've hidden all my scissors, so I won't cut my pads off. They've put them in my safe*.'

Janet also said that the staff locked food in her safe too, as a means of managing her weight: an amount of food is left out for her for each meal. I asked Janet if she found it helpful or not when the staff lock away her scissors and her food:

J: '*Not really, no…I have to wait till the staff come in until I can get my breakfast cereal out. I think that's a stupid idea*…
Int.: *So sometimes you find what the staff do helpful and sometimes you find it stupid*.
J: *Yeah*.'

Although Derek diverged from Janet in not appearing to find his staff team overtly punitive, there were moments in the transcript where he described being told he cannot or *'mustn't'* do something:

D: '*They don't let me do that…*
D: [Staff member E had said to Derek]: '*I mustn't stand on the settee. EVER. I mustn't stand on it. And I went like that* [mimes punching a glass photo frame on which he cut his hand].'

Derek was speaking quickly and loudly and seemed angry when he said this. I sensed that he felt thwarted by the staff and although the staff member's request for Derek not to stand on the sofa might have been borne out of concern for his safety, the extent of Derek's reaction (to self-harm by punching a glass photo frame and cutting his hand badly) suggests that he was angry. This allows for the thought that Derek might have experienced the remark as either punitive or infantilising. If the intention of the staff member was to demonstrate concern for his safety, Derek had not been able to receive it in this way.

6.5.3 An unwanted self

There were many areas of congruence within this rich, superordinate theme. Throughout the year spent participating in this study, both Derek and Janet were able to convey many aspects of themselves that they felt they needed to deny or hide from. Each of them strenuously denied their self-harming, placing it firmly in the past as something they used to do but now no longer engage in. It took time and, in Janet's case particularly, a specific way of using the music, to allow them to give voice to their self-harming. This was described in further detail in §5.8.

Both, when asked about the frequency of their self-harming, denied it and located it in the past:

D: '*Haven't done it at all. I've stopped doing that now*.'
J: '*I haven't done it at all. I used to do that but now I've stopped doing that altogether*.'

These almost identical answers, with their denial of self-harm, invite possible questions about the place of shame for people who self-harm:

Int.: '*Do you feel better after you have self-harmed?*
J: *I don't know…I think I feel a bit ashamed of myself sometimes*.

I wondered about the fantasies that Derek and Janet had about what I might think of them if they told me about their self-harming. The psychoanalytic concept of transference, described in §3.7.2, might offer a way of understanding what was happening here. Transference involves attributing feelings to people in the present that may have their origins in earlier or other relationships. In this example, both Janet and Derek knew that their respective staff teams considered their self-harming to be unwelcome. It might then have seemed a reasonable assumption for Derek and Janet to expect that other health professionals might feel the same way. If their assumptions were that their self-harming is unacceptable to other people, a strenuous denial begins to make sense. Janet, in particular, used the music to introduce the notion of her self-harming into the music therapy sessions. This was illustrated in the case study chapter in §5.8.

Derek and Janet both referred to a wish to disappear and not to think anymore. Although they were divergent in their manifestations, congruence was found in a shared wish to escape and avoid. For Derek this was usually expressed by saying that he could not remember in response to being asked a question. His staff team also confirmed that this is a technique Derek uses when he wishes to avoid thinking about something. Janet expressed her escaping and avoidance in a different way:

J: '*I just go to sleep. I just cover myself over. I've got a giant sized big blanket. I just cover it over my face*.'

Janet's response was to shut everything out and sleep. She acknowledged that she did this to make the time pass more quickly until the staff came back again a few hours later.

6.5.4 Positive changes

By the third SSI both participants reported a reduction in their self-harming, which was verified by their staff teams and addresses the primary research question: does the combined approach of weekly music therapy for the learning disabled service-user who self-harms and a monthly staff support group correlate to a reduction in the number of incidences of self-harm? Previously inexpressible thoughts and feelings had, through the music first, become available to think about and both participants were more able to acknowledge their feelings and how they related to their self-harming:

D: '*Sometimes I do get angry, yeah*.
Int.: *When I first knew you, when you got angry you used to self-harm. You say you don't do that so much now. So what do you do when you feel angry now?*
D: *I tell someone…the staff*.'

This extract from Derek's transcript also shows that he was taking responsibility for managing his feelings in a more positive way. Janet was also able to be much more proactive in attending to her legs in order to facilitate their recovery:

[Janet had reclined her chair and was sitting with her legs up, as instructed by the GP. Her staff team had often described her as being very reluctant to do this.]
Int.: '*Are you comfortable?*
J: *Yes. It helps my legs; it helps the fluid to go up my legs*.'

Janet's staff team had reported that she was taking much more responsibility across various aspects of her life, including doing her own washing up and trying to manage the results of her incontinence by putting wet things in the washing machine, rather than leaving these jobs for the staff.

In terms of music therapy, both participants experienced it as a positive intervention and there was congruence in them experiencing the sessions as having a calming effect:

D: '*Playing music helps me to relax…*'

J: '*It helps me to get all the stress out, it helps to take the stress away from other things that are on my mind some of the time….It's made me much happier in myself*.'

6.6 IPA of semi-structured interviews for the staff team of participant B

6.6.1 Superordinate themes for participant B's staff team

The cluster themes, extracted from the emergent themes and grouped together for their commonalities, fell into four distinctive groups which became the superordinate themes and are presented, with indictors, in the table below. Four superordinate themes emerged from the analysis of Derek's staff team's three SSIs: staff's undesirable feelings towards Derek; a caring staff team; staff team dynamics; and a hopeful staff team.

Superordinate and cluster themes	Page/ line	Indicators from transcript
Staff's undesirable feelings towards Derek		
hostile and aggressive feelings	5.17	'wipe (D's injury) with surgical spirit'
negative descriptions of D's destructiveness	3.3	'punch things, tear his clothes'
feelings of helplessness	37.19	'one step forward and two back'
nothing changes	37.9	'Derek's just Derek'
feeling stuck	46.5	'he has a lot of automated responses'
infantilise Derek	38.9	'it's like a tantrum'
A caring staff team		
genuine concern	70.26	'if you didn't care you wouldn't be here'
understanding of Derek	14.4	'if he feels badgered…that can be a trigger'
capacity to be moved by Derek	69.1	'fact that he did it all without being asked…I could have cried'
needing to prove themselves as good enough	40.18	'above and beyond trying to make it better for Derek'
Staff team dynamics		
negative feelings about themselves	19.22	'I feel like I've failed already'
staff rivalry/hierarchy	59.1	'accepts things from me…knows I'm at a different level'
anger at being manipulated	10.3	(1) 'I…got him to take his medication. (2) You won't get me like that again.'
blaming each other	5.22	'that was your fault'
A hopeful staff team		
change in staff perspective	52.18	'enabled us to step back…look at it differently'
staff view groups as helpful	54.21	it's helped no end'
staff feel more able to cope	72.13	… it's calmer; we just deal with it'
staff see benefits of music therapy	72.14	'(MT) has helped, definitely helped'
staff feel they have gained some knowledge	86.17	'(you) feel like you've got a bit of that knowledge as well'
staff can adapt and change	86.2	'now we learn from our mistakes'
staff are less self-punishing	83.2	'try to accept now, reflect on it'
staff function better as a team	72.3	'feels like we are a proper team'

Tab. 6.4: Table of superordinate themes for participant B's staff team

6.7 IPA of semi-structured interviews for the staff team of participant F

6.7.1 Superordinate themes for participant F's staff team

The cluster themes, extracted from the emergent themes and grouped together for their commonalities, fell into four distinctive groups which became the superordinate themes and are presented, with indictors, in the table below.

Four superordinate themes emerged from the analysis of Janet's staff team's three SSIs: a staff team that needs to feel good enough; a staff team that still has negative feelings; a staff team that has shifted its view of Janet; and a staff team that can acknowledge positive changes.

Superordinate and cluster themes	Page/ line	Indicators from transcript
A staff team that needs to feel good enough		
appreciated by their managers	3.17	'They do praise us, they'll send lovely little text messages'
competitiveness about who can stop Janet from self-harming	49.12	'I managed to stop her…peeing herself for a week by bribing her with chocolates every day.'
showing how protective of Janet they are	90.4	'I always say to her: "Don't answer the door."'
going above and beyond duty	111.10	In that really bad snow, I was going from one person to another to another. It was so hard.'
A staff team that still has negative feelings		
Staff feel repulsed by Janet's self-harming	2.1	And she says: "Does it look all right?" and I say: "No, it looks like a squashed hedgehog on the road. It's disgusting."'
struggle to cope with Janet's self-harm	2.2	'You are so depressed, you are almost in tears.'
Staff experience Janet's self-harming as personal	17.7	'But's it's a slap in the face with a wet kipper when…you turn up and her leg is covered in gunge and has been messed around with and peed on.'
staff can infantilise Janet	28.8	'When she's good , she's very, very good, but when she's bad she's naughty'
a sense of never feeling good enough	46.10	'No matter how good you are, you will always come up for scrutiny.'
staff feel they have let Janet down	99.4	'I feel like I've let her down myself'
A staff team that has shifted its view of Janet		
Staff can be moved by Janet	50.20	'It broke my heart.'
staff can show empathy towards Janet	65.12	'I can understand how she's feeling.'
staff can appreciate Janet's thoughtfulness	78.11	'she was so thoughtful and she gives you a little cuddle and was like: "Are you alright?"'
staff can be pleasantly shocked by Janet	87.2	'that did shock me how empathic she was towards me'
can be complimentary about Janet	94.16	'It looks lovely on her…really gorgeous.'
compliment Janet on her skills	98.5	'You didn't see how she folds her washing. She's immaculate.'
A staff team that can acknowledge positive changes		
staff found the monthly staff groups useful	56.10	'I think it's good for us to think about how working with Janet makes us feel.'
staff can acknowledge changes	63.6	'She hasn't done that (poked sharp objects down her bandages) for a long while now.'
staff more positive about Janet's legs	63.7	'Her legs are in really, really good condition'
staff know that Janet's self-harm is not a personal attack on them	100.15	'I don't think she goes out of her way to be incontinent…I don't think she does it to annoy us.'
staff can see staff groups as cathartic	104.15	'let our emotions out…it's nice to get it off your chest…'
staff can see some benefits of music therapy for Janet	113.7	'I do think she's developed quite a bit of insight since coming to music therapy.'
staff can see how music therapy has helped Janet	113.11	'I think she's been able to express herself with you and she's definitely more empathic now.'

Tab. 6.5: Table of superordinate themes for participant F's staff team

6.8 Master table of themes for both staff teams

The table below shows the superordinate themes that have emerged as a result of synthesising the superordinate themes from each of the two staff groups. Decisions were taken about which themes to prioritise; these were determined by a combination of prevalence within the transcript and the richness of the theme. These were then distilled into this final master table of themes.

The two staff teams were invited to think about their responses to their service-user's self-harming. The SSI topics focused on method and frequency of self-harming, how the staff team understood and experienced the self-harming, how they responded to it and whether or not they thought music therapy and the monthly staff groups had been helpful to their service-user and themselves respectively.

The accounts given by the two staff teams generated these four superordinate themes: a staff team with unwanted feelings; a staff team that needs to prove its worth; a staff team with difficulties within itself; and positive changes. Within each of these themes there were degrees of congruence and divergence in how the two staff teams expressed the superordinate themes.

Superordinate and cluster themes	Page/ line	Page/ line
Staff teams with unwanted feelings	**Derek**	**Janet**
feelings of repulsion towards service-user's self-harming	28.28	17.8
aggressive feelings towards service-user	5.18	2.1
graphic descriptions of self-harm	4.15	32.2
feeling stuck	37.9	22.11
can infantilise their service-user	38.9	28.8
Staff teams that need to prove their worth		
staff need to feel good enough	40.18	111.10
staff team with a duty of care	7.18	3.11
frustration when people assume their job is easy	35.17	56.11
Staff teams that struggled		
negative feelings about themselves	19.22	99.7
staff splitting/hierarchy	10.3	49.12
the work feels difficult	21.19	110.6
staff carry the blame	22.16	41.9
staff project their wishes on to their service-users	13.14	50.13
Positive changes		
reduction in self-harming	64.21	63.7
genuine concern for service-user	70.27	108.12
can be moved by the service-user	69.3	101.17
a changed view of the service-user	71.18	87.2
positive impact of music therapy	72.14	113.11
staff groups as helpful	54.21	60.10
staff less self-punishing	83.2	100.17

Tab. 6.6: Master table of superordinate themes for staff groups

6.8.1 Staff teams with unwanted feelings

This was a very significant theme in terms of prevalence and richness throughout the transcripts for both staff teams. In the first and second SSIs for both teams there was a high prevalence of staff expressing disgust and repulsion about their service-user's self-harming. There was divergence in terms of how this was expressed to the service-user. Derek's staff team seemed to be able to contain this more easily, using the staff groups to think about how they experienced Derek's self-harming. Janet's staff team found it difficult to hide their feelings of repulsion from her:

'*Sometimes she will try and hide it. You'll walk in there…you'll go: "Oh my God, what's happened to your leg?"*
Oh well, I had an accident last night and I've tried to cut me bandage off.
And you'll go: "Urgh, yuk, look at that.'' '

There was congruence in the expression of aggressive, hostile feelings towards Derek and Janet from their staff teams. In both of these examples staff were struggling to manage very ambivalent feelings towards the service-users they support. In this next example, one of Janet's staff has noted that Janet has had an episode of urinary incontinence:

'*I just go: "Have you had an accident?" and then I take her trousers down and say: "So why are your trousers wet then?*" '

Both of these examples happened in the first SSIs. It was difficult for the staff teams to think about the effect of their words or the strength of feeling that lay behind them. The SGFs and myself were aware of how angry the staff teams felt, both with the higher managers who the staff teams perceived as having little idea of the demands of their work and the service-users who created mess, both literally and emotionally, for the staff to deal with. Their graphic descriptions of self-harming felt like a projection into me of all that they found intolerable in their service-users. Projective identification, first described by Klein and discussed in §3.7.8, is an unconscious mechanism by which feelings, thoughts, motivations and desires that are considered unacceptable to the person experiencing them are then attributed to another person. The repudiated feelings

are then projected into another person so that they experience the original, intolerable feelings. Janet's staff team, in particular, described her self-harming in such a graphic way that it had the effect of making me feel unwell. I felt as though they were trying to evacuate the mess of Janet's self-harming. In the monthly staff groups, both staff teams were able to think about some of these more difficult, indigestible feelings and have them heard and understood. This enabled them to come to different ways of experiencing and responding to episodes of self-harming. By the final SSI, although there had been a significant reduction in self-harming for both participants, when episodes did occur, both staff teams were able to express a much more compassionate view as a result of having had their earlier feelings recognised and thought about.

6.8.2 Staff teams that need to prove their worth

It was very noticeable, particularly in the first SSIs for both staff teams, that they needed to show me how hard they tried, how hard they worked and how committed they were to their service-users. Phrases such as *'we go above and beyond'; 'it's really hard'; 'we really go all out to make (things) better'; '*[service-user's sister] *wrote a letter to our bosses telling him how wonderful we are'; 'if you didn't care, you wouldn't be here'* were richly represented by both staff teams. I was interested in the timing of these comments within the transcripts: they often followed a comment or series of remarks in which the staff teams' more ambivalent or hostile feelings towards their service-user might have emerged. This staff group seemed to struggle with their identity as carers: people who are paid to care. The title of 'carer' seemed to leave little room for them to acknowledge healthy, yet unwanted, feelings that seemed in direct opposition to the caring feelings they felt they were supposed to have. Reminding me and themselves of how hard they work and how committed they are to their service-users might be an effective way to replace their ambivalent feelings with something that felt more palatable to them. There will be further reflection about the ways in which the staff teams identified as carers in §8.1.4.

Further congruence within this superordinate theme was found in the frustration that both staff teams expressed when people perceived their jobs to be easy:

'*I think most of all it's frustrating to think that this is seen as an easy place to work. It really is…when you come in and do the odd shift for a few hours… people behave differently, so actually they are not getting the normal sense*.'

'*Someone said to me that being a carer must be a really easy job and I was so angry. I thought: "You wanna try doing my job for a week*.'' '

Within both examples, one from each staff team, is the implication that nobody could really understand what their jobs are like and how difficult they are. Both teams told me how much you have to really care about people in order to do this poorly paid work. This suggested to me that people might feel undervalued, a thought that was later confirmed by a member of Janet's staff team:

'*People say what do you do for a living and I say: "I wipe backsides, I clean backsides. And floors…and toilets*."
Int.: *So it feels like you deal with all the mess*.
…it pays some of the bills, I wouldn't say all the bills…but I wouldn't do anything else.'

I was very struck by the final comment, '*but I wouldn't do anything else'.* This seemed to be another example of needing to negate the negative feelings expressed about the job with something more acceptable: in this case a comment to suggest that the staff member has chosen this work, perhaps for altruistic reasons.

6.8.3 Staff teams that struggled

Both staff teams spoke of carrying the blame when their service-user self-harmed. There was congruence in people wondering what they might or might not have done to prevent an incident of self-harm and examining themselves to see if they could have done anything differently. Phrases such as: *'I feel like I've failed already'; 'what have I done?'; 'how could I have done things differently?'* peppered the transcripts of both staff teams. Staff teams seemed to expect scrutiny either from upper management or family members of their service-users:

'*No matter how good you are, you will always come up for scrutiny*.'

The feelings expressed suggested that whatever the staff teams did was never good enough. Staff spoke of feeling personally responsible when their service-user had self-harmed:

'*You feel personally like you've let her down because she's still carrying on doing it* [self-harming].'

Further congruence lay in the frustration and disappointment expressed when their service-user self-harmed, especially when there had been a significant length of time where this had not happened. Both teams placed a lot of responsibility upon themselves for whether or not their service-user self-harmed, with perhaps the unconscious fantasy being that they had the power to control whether or not Derek and Janet self-harmed:

'*Why did he DO that? I mean…weeks…we've got all this in place, this has been going brilliantly. WHY?*'

The frustration and exasperation are palpable here; the capitalisation indicates words that were spoken in a raised voice. The staff member seems to experience Derek's self-harming as a personal attack on everything that she had got into place for the last weeks which had been going brilliantly. Did she experience Derek's self-harming as spoiling her efforts? I wondered if the staff teams felt that the efforts they went to for their service-users, particularly in terms of organising days out for them, were interrupted by episodes of self-harming. Both staff teams expressed their frustration in subtle ways by reminding their service-user of what they could be doing instead:

'*You could have had a really nice day out but instead you're sat in the hospital*.'

'*Just think of all the things we could do instead, but now we're gonna have to go back to the doctors*.'

The painful, nonsensical (to the staff teams) part of this is that both Derek and Janet understood exactly what was on offer in terms of a day out; therefore, by self-harming, they were in fact making a choice, albeit one that was difficult for the staff teams to bear.

6.8.4 Positive changes

By the end of the study, both teams were feeling more positive about their service-users both in terms of the frequency of self-harming and more general changes in their relationships with Derek and Janet. There had been a significant reduction in self-harming for both participants, in spite of Janet's urinary incontinence continuing to be a concern. She was no longer sticking things down her bandages and scratching her legs and her legs had healed to a point that some staff members had not seen before; certainly her staff team felt that this was the longest that they had known Janet's legs to have good skin integrity. Derek's staff team felt that self-harming was less of a significant issue for him:

'*…I don't really think the self-harm is so much of an issue now*.'

This addresses the principal research question of whether the dual approach of weekly music therapy for the learning disabled service-user who self-harms and a monthly staff support group correlated to a reduction in the number of incidences of self-harm.

Both staff teams, by the final SSI, were able to speak of being moved by their service-user: they could notice and respond to acts of kindness that Derek and Janet showed towards the staff teams. In this excerpt Derek, without being asked, had washed up a large pile of dishes:

'*The fact that he did it all without being asked…*'
'*I could have cried*.'
Int.: '*So did he see that reaction in you?*'
'*Oh, we had a hug. That's what keeps you going, those split seconds…'*

The staff member was really able to express how moved she was by Derek's gesture and how important such moments were for sustaining her in her work. Similarly, when a member of Janet's staff team returned to work following surgery, she was shocked by the extent of Janet's empathy towards her:

'*She'll always give you a cuddle, but you never have that empathy from her. She's always laughing at you, but that did shock me how empathic she was towards me*.
Int.: *That sounds new*.
Yeah, that's a very new thing.'

Staff were able to notice and attend to these positive moments and allow them to stand without being erased by a negative incident. Both excerpts show a change from the beginning of the study where there was little expectation from the staff team that their service-users might be able to move them or to surprise them. For both staff teams, things were very stuck and hopeless with no prospect of change:

'*Derek's just Derek…he's always gonna be up and down*.'
'*I don't think we are going to resolve Janet's issues…I think Janet will continue to do this* [self-harm] *for the remainder of her life*.'

There was a significant shift from a position where change was not imagined to be possible to a point where both staff teams could see changes in their service-users. Each of the teams also found new, more compassionate ways of responding to their service-users, particularly if there had been an incident of self-harm. Derek's staff team were much more attuned to his moods and became more proactive in seeking him out to talk to him before an incident of self-harm occurred. They were also much more reflective and empathic regarding his lack of family and became very imaginative about how difficult this was for him. By the final SSI, Janet's staff team were much more compassionate around her self-harming. Rather than experiencing it as personal and manipulating, and responding with frustration, by the end of the study staff were able to express their sadness when Janet self-harmed and to understand it as coming from a position of loneliness and anxiety. Asked how they felt when Janet self-harmed, two members of her staff team had this exchange:

'*You feel sad*.
'*Especially when you see the state of it* [her leg] *sometimes, you're like: "Ah Janet, that must be so painful…*''
Well, you don't want anyone you care for to be in pain, do you?'

6.9 A clinical vignette demonstrating a change of perspective for participant F and a member of her staff team

The following vignette gives an example of how both participant F and her staff team gained new perspectives over the course of this study. One of her carers had remarked on Janet's change of view in regard to the possibility of moving:

'*When I went [to see Janet] the other night…and we was talking about how a year ago when she was going through a really bad patch…I said to her then: "Oh wouldn't you like to move out of here"…and she was like: "No, the only way they're taking me out of this flat is when I die…This is my flat. They can't take me away from my flat. This is mine." But when I was there last week, I asked her the same questions and I said: "You do get lonely at night…we all know that because you are on your own" and I said: "would you ever consider moving out of here and going to live in a care home or with other people?" and she went: "Yeah, I would." And I was like, so shocked.*'

This represented a considerable change in perspective for Janet, but what is also significant about this excerpt from the transcript is a change in how the staff member addressed the issue of Janet potentially moving with her. This addresses, in a positive way, the secondary research question of whether the staff's attitude changed in relation to supporting adults with learning disabilities who self-harmed as a result of participating in the monthly staff groups. In the above extract the staff member describes asking Janet the same question twice. Closer examination of what she actually said reveals some subtle but important changes in how she framed the question when she asked it for the second time. At the first time of asking how Janet would have felt about moving into different accommodation, the staff member framed the question in a way that suggested that she thought Janet should want to move out of her flat: *'Wouldn't you like to move out of here?'* The staff member seems to be expressing her own opinion through the question. However, when the question was asked a second time, a year later, the staff member began from the premise of an understanding of Janet's loneliness and asked: *'Would you ever consider moving out of here and going to live in a care home or with other people?'* The use of the words *'like'* and *'consider'* in the context of these questions could potentially suggest a different meaning: *'consider'* feels much more open to careful thought, reflection and a curiosity about what Janet might want for herself; *'like'* in this context, could possibly be seen as the staff member

suggesting that this should be what Janet would want. In the second asking of the question, the staff member has offered Janet alternatives to consider: *'a care home or with other people.'* This may have enabled Janet to think more creatively about what types of alternative accommodation might have been available to her. The fact that the staff member was first able to acknowledge how lonely Janet was in her flat ,and to show a sensitive understanding of this, perhaps allowed Janet to receive and respond to the question differently from how she did when it was put to her a year earlier.

This example shows change in both Janet's responses: an openness and availability of thought for something that previously had been completely unacceptable to her. It also demonstrated a change in how a member of her staff team had been able to approach her, a change which was reflected in a more general, positive change in how participant F's staff team responded to her.

6.10 Staff teams' views of music therapy for their service-users

For both staff teams, music therapy and the monthly staff groups were felt to be effective. Within Janet's staff team there was some divergence in whether or not Janet had enjoyed coming to music therapy, but further exploration of this in the final SSI revealed a difficult journey where Janet had to walk a long way. The physical discomfort for Janet became part of her experience of attending the sessions and it was difficult to separate the journey, part of the framework around the session, from the session itself. I sought to address this by seeing her at home for the last six sessions. However, the staff team felt that Janet had been able to express herself within music therapy and had become a more empathic person. They also felt that she had a greater insight into her self-harming as a result of having had music therapy and that new conversations were being had about the possibilities of different living accommodation for Janet:

'*I do think that she has developed quite a bit of insight since coming to music therapy and can say much more about being lonely. She is clearly thinking about moving whereas, at the start of this work, as you was saying* [to another staff member]*: "This is my flat, I'm not moving", whereas now we are having conversations that weren't possible before*.'

Derek's staff team also felt that he benefitted from attending music therapy:

'*And I think the music therapy has definitely helped, because…he can talk about stuff that's bothering him…he is able to play it out through music…you can see the benefit to him afterwards*.'

6.11 The staff teams' views of the monthly staff groups

The staff groups were also experienced as helpful by both staff teams, although Janet's staff team also acknowledged that they found them difficult because of the intensity of feelings that were generated when they stopped working and spent time together in a different way, thinking about the experience of supporting Janet:

'*I didn't realise that I felt this and I felt that. You're just: "Oh my God*." '

There was congruence in both teams feeling that the monthly groups had helped to foster a sense of understanding between them:

'*I think the groups with* [the SGF] *have helped us to understand and support each other*.'

'*But as far as the groups in this study go, they've helped no end, because people did used to take stuff personally…it feels like we are a proper team and we respect each other and the consequences of that obviously affects everyone and you can see how ultimately that helps Derek…*'

Derek's staff team expressed the difference between not coping before the interventions offered in this research study and a sense of feeling more able to cope by the end:

'*But it is the music therapy and the staff meetings that are helping us. Our little groups that have had the meetings have helped us to think about Derek in a different way. We felt before like we weren't coping with it…now as a team we feel we cope better because we had an outlet*.'

In the next section there will be further reflection on the results, using excerpts from the transcripts to support outcomes that show a reduction in the frequency of self-harming.

6.12 Correlations between service-user and staff team results

This section will show correlations between the accounts of the service-users and their staff teams. The previous master table distilled the results of the participants and then the service-users, looking for congruence and divergence in both separately. In this section, the results will be further distilled to demonstrate correlations between each service-user and their corresponding staff team. Evidence from the transcripts will support outcomes and thereby address the main research question. Starting with an examination of the data pertaining to any reduction in self-harming for the service-users, it will show, using quotations directly from the service-users and staff teams, congruence and divergence between the accounts of the service-users and their staff teams about whether the frequency of self-harming has reduced for the two service-users.

6.12.1 Correlations between participant B and his staff team

For the two participants in the research project, receiving weekly, individual music therapy for one year correlated to a reduction in self-harm. As discussed in §3.1.1, change in terms of a reduction in the frequency of self-harming was measured numerically and was evidenced by standardised reporting that the staff teams had to complete for their employers. Any issues of challenging behaviour, including self-harming or accidents, were reported through this mechanism. Change was also measured through the reports of the service-users and their staff teams through the SSIs. The following extracts demonstrate a change in the frequency of self-harming over time, reported in the words of participant B and his staff team through the SSIs.

6.12.1.1 Outcomes for participant B

Self-report	
SSI One	Int.: *'So in this last week, have you hurt yourself on purpose?* Participant B: *Yeah…you know my picture frame?…Punched straight through the glass and that's all running down with blood… I was very cross.'*
SSI Three	Int.: *'So in this last week, have you hurt yourself on purpose at all?* Participant B: *No, I haven't. Not at all…I've been able to calm myself down.'*

Participant B's self-reporting of a reduction in his self-harming across the year of the study shows congruence with his staff-team's reporting of the frequency of his self-harming across the year.

Participant B's staff team	
SSI One	Int.: *'Can you tell me how many times Derek has self-harmed over the last four weeks?'* Staff team member: *'There have been seven or eight incidences.'*
SSI Three	Int.: '*During the past four weeks how many times has Derek self-harmed?'* Staff team member: *'He hasn't in the last four weeks…I don't really think the self- harm is so much of an issue now.'*

These extracts reveal that there is congruence between participant B and his staff team in their accounts of the presence of self-harming within the given timescales of the first SSI and an absence of any self-harming at all within the given timescales of the third SSI.

6.12.2 Correlations between participant F and her staff team

This section will show any correlation between the reports of participant F and her staff team in relation to her self-harming.

6.12.2.1 Outcomes for participant F

Self-report	
SSI One	Int.: *'So, during this last week, have you hurt yourself on purpose?'* Participant F: *'I haven't done it at all* [shifts uncomfortably in chair]. *I used to do that but now I've stopped doing that altogether.'* Int.: *'So how is your leg at the moment?'* Participant F: *'I have poked it quite a few times.'*
SSI Three	Int.: *'So in the last week since I came and saw you last Thursday, have you hurt yourself on purpose?'* Participant F: *'No I haven't. No I haven't. Wait a minute: I did fall over, but that was an accident!…I think the accidents* [of incontinence] *are getting a bit better too. I keep going to the loo every time.'* Int.: *'OK, I was also thinking about sticking things down your bandages too.'* Participant F: *'Oh yes, I used to do that but I haven't done that for a long time now.'*

Participant F's staff team	
SSI One	Int.: *'So, looking at the last four weeks, how many times has she either interfered with the healing of her leg or been incontinent of urine?'* Staff team member: *'I would say that interfering with her stocking has not been so great, fourteen times over the last month, she's doing that and shoving things down them to scratch it. The peeing is every day.'*
SSI Three	Int.: *'So, in the last four weeks, how often is Janet self-harming? I know when we refer to self-harming for Janet we are thinking about two things: firstly the urinary incontinence and secondly her poking things down her bandages to scratch and aggravate her legs until they bleed.'* Staff member: *'She hasn't done that for a long while now…'* Staff member: *'She's doing really, really well but she is still urinating most days and not wearing her pads.'*

6.12.3 Interpreting the data in relation to Janet's self-harming

Self-harming for Janet consisted of two components as indicated above. One aspect of her self-harming was when she stuck sharp objects down her bandaged legs to relieve the itching, often scratching her legs until they bled. There was congruence between Janet's and the staff team's accounts in reporting that this was something that Janet no longer engaged in. The other aspect of Janet's self-harming was her urinary incontinence. There was some divergence between Janet and the staff team about how frequently this was happening. Staff reported that this was happening every day; Janet reported that it was getting better and she was having fewer wet bandages in the mornings. One of the difficulties in generating accurate data here was due to the structure of how her community staff team worked. Different staff visited Janet every day according to a rota system. This staff team clearly worked under significant pressure: if Janet had been incontinent and staff had to deal with this, they were inevitably late for their next community visit and this had a lasting impact on the rest of

their day. Sometimes, the recording of information about Janet's incontinence was overlooked if staff were in a rush. There would be variations in how often each member of Janet's staff team visited her in any given week: one member of staff might see her almost every day; another staff member might see her twice a week. This may account for discrepancies in the data between the staff team's account of how many times a week Janet was incontinent of urine: for the staff member that arrived to find Janet had been incontinent, but who actually only visited her twice a week, it felt like every time that staff member visited Janet she had been incontinent. This did not feel like an improvement. The staff member who visited almost every day and had some experiences of arriving at Janet's to find that she had not been incontinent expressed this as a small sense of improvement. This had an impact on the accuracy of the data generated in relation to Janet's urinary incontinence.

6.12.4 Reporting about the condition of Janet's leg

It was much easier for staff to comment with greater accuracy on the condition of Janet's leg because this was something each staff member saw when they assisted Janet with her personal care. I will therefore include a further outcome report based on the objective condition of Janet's leg and how this corresponded to the number of times Janet needed to visit the GP surgery each week:

Self-report	
At the start of the study	*'Yeah, it has broken out again. It bleeds, the bandages are covered in blood.'*
At the end of the study	*'It's all healed up now.'*

Reports from the staff team	
At the start of the study	*'And sometimes it stinks…you'll go in and her leg will be soaked with pus and blood and yellow and green and God knows what.'*
At the end of the study	*'Her legs are in really, really good condition at the moment.'*

There was also congruence in both Janet and her staff team reporting that visits to the surgery for dressing changes had decreased from three times a week to once a week by the end of the study.

6.13 Summary

Both Janet and her staff team confirmed that her legs were completely healed by the end of the study, with one member of her staff team reporting that she had never known the skin integrity of Janet's leg to be so good. Derek and his staff-team reported that self-harm was something that Derek hardly engaged in by the end of the study.

For both participants and their staff teams there was mostly congruence between their accounts about the frequency of self-harming across the study. There was some divergence between what Janet and her staff team said about the frequency of her urinary incontinence; possible reasons have been suggested for this discrepancy in the data.

Chapter 7: Discussion of Results

7.1 Introduction

This chapter discusses how the study has answered the research questions. It begins with a summary of the main findings and these will be discussed within the context of the current literature. Following this, there will be a discussion about the method, including the study design, the data collection and analysis.

7.2 Summary of the thesis

This research study has investigated whether the combined approach of weekly music therapy for the learning-disabled service-user who self-harms and a monthly staff support group correlated to a reduction in the number of incidences of self-harm. It also considered whether staff's attitudes changed in relation to supporting adults with learning disabilities who self-harmed, and also whether staff's understanding about the nature and impact of self-harm increased, as a result of participation in this study.

The gap in knowledge that I sought to investigate is whether the combination of offering an intervention to the staff team alongside music therapy for the service-user resulted in a positive outcome for both. I was interested in the interaction of the staff team upon the service-user and the ways in which, if staff teams feel unattended to, it can, in my clinical experience, give rise to envious attacks on the music therapy. For example, I have heard members of staff express sentiments like:

'*It's OK for him getting to bang a drum for an hour*.'
'*I could do with a bit of therapy myself*.'

Comments like this, made in front of a service-user imminently before or just after a music therapy session, can undermine the work as well as contribute to a divisive relationship between the service-user and the staff member. This research study seeks to ameliorate such envious attacks by offering an intervention to the staff team

alongside music therapy for the service-user. By doing this, it was hoped that the potential benefits of music therapy could be optimised, unaffected by the projections of the staff team who were receiving support in their own right.

7.3 The main findings

This study indicates certain positive correlations between the interventions offered (music therapy and staff groups) and a reduction in self-harming for the service-users and increased understanding about self-harm for the staff teams:

- for the two learning-disabled service-users who self-harmed, engaging in weekly music therapy for one year correlated to a reduction in the number of incidences of self-harm for them both;

- for the two staff teams, participation in a monthly group that allowed the opportunity to reflect on the demands of their role and the challenges in supporting somebody who self-harms, correlated to an increased understanding about the nature of self-harm and its meaning for the person engaging in it. This understanding seemed to correlate to a change in how staff were able to respond to the service-users they were supporting.

The methods for measuring these changes were discussed in §3.1.1.

This study did not set out to suggest exactly which interventions correlated to particular changes; the nature of this study was to investigate the dual approach of interventions for both service-users and staff teams and to see if this correlated to broader positive outcomes as described in the research questions.

7.3.1 Other significant findings

Other significant findings from this research project were that:

- this research was needed;

- the service-user participants in this research study found music therapy to be a positive intervention;

- the staff team participants in this research study found the monthly staff groups to be a positive intervention;

- using qualitative data generated through semi-structured interviews and analysed within an IPA framework generated rich data about the participants' experience;

- it is important for care staff to have a space in which to explore negative feelings associated with their role.

7.4 Reflections on the findings

Chapter 6 showed, through the synthesis and master table of themes for the two participants, that there was a positive correlation between receiving music therapy and a reduction in the frequency of self-harming. For the staff teams, there was also a positive correlation between engaging in the monthly staff groups and their understanding of what self-harm meant to their service-user. There were also significant changes in how the staff teams came to feel about their service-users and how they responded to them when they did self-harm.

7.4.1 The research was needed

An extensive review of the literature found that, historically, the emotional lives of people with learning disabilities have been neglected (Arthur, 1999; Sinason, 1992). In the introduction to her book *Mental Handicap and the Human Condition — new approaches from the Tavistock,* Sinason writes:

‘Handicapped adults and children are still too rarely seen to have words and thoughts of value inside them and only too rarely provided with a means of interpreting them or having them interpreted.’

(Sinason, 1992, p. 3)

People with learning disabilities are likely to encounter difficulties in communication which can lead to emotional and behavioural challenges. Those that, in addition, have experienced adverse life events may experience a greater incidence of mental illness and may engage in behaviour that challenges staff teams and services, of which self-harming might be one example. Whilst music therapy is a highly effective intervention in addressing the emotional and social needs of adults with learning disabilities (Gale, 1989; Heal, 1994), there has been very little research in music therapy with adults with learning disabilities that self-harm (Lawes and Woodcock, 1995; Ford, 1999). The literature search revealed high levels of staff burnout in care staff working with this client group (Hill and Dagnan, 2002; Snow, Langdon and Reynolds, 2007; Duperouzel and Fish, 2007) and a need for staff teams to have better support (Hastings and Remington, 1994; Fish, 2000; Gough and Hawkins, 2000; Thompson, Powis and Carradice, 2008; Heslop and Macauley, 2009). This is the first research study to simultaneously address the needs of service-users who self-harm through music therapy and of staff teams through a separate intervention and to ensure that, in both interventions, the voices of the participants were represented and central to the study.

7.4.2 Service-users found music therapy to be a positive experience

Both service-users and staff teams spoke openly about their experiences of being involved in this research project, with each of the service-user participants reporting positively about their experience of music therapy during the SSIs. They reported an increase in confidence and a greater awareness of their feelings. Both said that they felt more able to speak to their staff teams about feelings that previously might have led to an episode of self-harming. Engagement in co-improvising was acknowledged as being important and meaningful for both participants with each expressing this, rather than the opportunity for talking, as the more important aspect of music therapy for them. Both were able to use music to express emotional states that could not easily be put into

words, even though both had language available to them. Each service-user was motivated to use the instruments and spoke of the value in being able to express their feelings through music. During the final SSI participant B said he had found it helpful to both play music and talk:

'*It helps me to come here. I can come and talk to you about things. Playing music helps me relax and I can talk about me Mum and Dad*.'

Participant F reported an increase in her self-confidence as a result of attending music therapy:

'*It's made a difference. It's made me feel different. It's made me feel much happier in myself…I feel like I've got my confidence back.*'

In her final improvisation in the last session, participant F returned to playing the little frog guiro which had become so important in the earlier sessions for bringing the notion of Janet's self-harming into our consciousness (see §5.8). Previously its use had represented something for which words could not be found, namely the irritated, inflamed condition of Janet's legs, brought about by a combination of urinary incontinence and Janet's attempts to ameliorate the itching by putting sharp objects down her bandages to scratch her leg. Now, the frog guiro represented something funny: Janet thought it sounded like a duck quacking and fell into fits of giggles at this thought. Whereas Janet had always had a tendency to be cheery and upbeat about things, even when the actual situation did not necessarily warrant such a response, this felt genuinely humorous and we laughed together. By the end of the work, Janet's leg had almost completely healed so perhaps it felt safe enough to laugh at the guiro given its earlier meaning in the work. The ocean drum reminded Janet of a horse and she was able to imagine what it might be like to gallop off somewhere. I was very struck by Janet's freedom of imagination when she engaged in music-making. She was very creative and throughout the work became much more adventurous about trying new instruments and experimenting with different ways of playing them. For Derek, similarly, music had given him the freedom to express some of his deepest feelings around the loss of his parents and give voice to some of the more destructive feelings that could lead him to self-harm.

7.4.3 Staff teams found the monthly staff groups a positive experience

Other studies, discussed in §2.8, have expressed a correlation between how staff understand self-harm and how they respond to it (Dick et al., 2011; Mitchell and Hastings, 2001). This PhD research project shows congruence with this view: that staff who feel negatively about a service-user's self-harming are more likely to respond to the service-user in a depersonalising way. This justifies the need for a space where staff can, in a non-judgemental atmosphere, acknowledge some of their more negative and perhaps unwanted feelings towards their service-users, as well as finding support and validation from their colleagues for the aspects of the work that feel challenging. This study showed that once some of these difficult feelings had begun to find a voice in the monthly groups and could really be thought about and understood, staff were gradually able to come to new ways of thinking about their service-users and the possible meanings that self-harm had for them. By the end of the study, there were striking differences in how both staff teams spoke about their service-users compared to how things were at the start of the study: both teams had a much more compassionate view of their service-user; both teams enjoyed spending time with their service-user and appreciated the changes that they were beginning to make in their own lives. There was an acknowledgement that, in spite of their expectations that nothing could ever be different, things had indeed changed and the self-harming had reduced for both participants. Both staff teams were able to articulate the benefits to having participated in the monthly staff groups, as well as the challenges that the groups had posed for them. Staff were able to acknowledge how, in some ways, it was easier not to think too deeply about their service-user's self-harming and just *'get on with the job'.* Far from being an unfeeling view, this emerged as a strategy that some staff members used as a way of coping with something that felt unbearable. Both staff teams reported finding new ways of understanding what self-harming meant for their service-user and had come to new ways of responding to it when it did occur. There was further congruence in both teams feeling well-supported through the monthly groups and a stronger sense of team cohesiveness by the end of the research project, particularly for participant B's staff team. Both staff teams reported improved levels of understanding the emotional world of their service-user and reduced levels of stress when responding to an incident

of self-harm. Participant B's staff team highlighted the positive impact on their service-user as a result of them functioning like *'a proper team now'.*

7.4.4 Qualitative data generated through semi-structured interviews and analysed through an IPA framework generated rich data about the participants' experience

The use of SSIs in this research study to generate data has resulted in rich, detailed descriptions of both the service-users' and staff teams' experiences. This supports other studies that have also shown that the use of SSIs is an effective way of generating rich data in qualitative research (Denzin, 1989; King and Horrocks, 2010). For participant B's staff team, it was meaningful for them to be invited to take part in research and to feel that their views were of interest and relevance to other people, as this excerpt from their final SSI shows:

Int.: '*You have made an important contribution to how we think about and understand people with learning disabilities who self-harm and how we try to support staff teams*…'
'*I feel like taking that last bit and putting it in a letter and then send it to* [names manager].'
'*Seriously, send it to them*.'
'*The whole thing about helping with research, that's really good*.'
'*It's not something we've been asked to do or been involved in before and I've enjoyed it*.'

7.4.5 Importance for care staff to have a space in which to explore negative feelings associated with their role

Evidence suggests that staff teams working in the area of supporting adults with learning disabilities and challenging behaviour experience higher than average levels of staff burnout, with up to a third experiencing stress levels indicative of a mental health concern (Skirrow and Hatton, 2007). As discussed in §2.8, Lawson and O'Brien (1994) made a connection between staff experiencing high levels of stress and engaging negatively with their service-users. The findings from this PhD study support Lawson and O'Brien's outcomes and also show that attending to staff teams who are engaged in work that they experience as difficult is a protective factor against engaging negatively with their service-users. The SGFs and I were able to consider the ways that care work can put people in touch with difficult and powerful feelings. Fish and Reid (2011)

explored two staff teams working with people with learning disabilities who self-harmed within a forensic facility. The authors suggest that self-harming might be seen by the staff as 'deviant or rule-breaking', resulting in staff perceiving the service-user as 'bad'. They argue that this can lead to a deterioration in the relationship between staff and service-user which may affect the quality of the care delivered to the client. Hastings and Remington (1994) found that some responses of staff can actually maintain and encourage challenging behaviour in service-users. Taking these two ideas together: that negative feelings arising from this kind of work are common and that there is a correlation between negative feelings and how this impacts upon how staff teams respond, the need to offer staff teams a space to reflect on the feelings generated by this work seems very important. In the study by Fish and Reid, a staff member said:

'*Staff need clinical supervision, actively clinical supervision at least every week…you just need to be able to…say how you feel*.'

(Fish and Reid, 2011, p. 155)

The staff member went on to say that ideally they would want to talk to someone that knows about self-harm, possibly a clinical supervisor but not a manager. The reason given was concern that a manager might report any negative feelings the staff member expressed. The conclusions from the study were that staff need 'support, education and counselling' to process feelings of guilt and other distressing feelings arising from the work. This research study responds to these findings by offering groups to the staff teams that encompass the domains of support, education and counselling mentioned above.

Chapter 8: Reflections and Conclusion

This chapter will reflect upon how this study contributes to knowledge and what the impact of this research has been so far. The chapter will conclude by looking ahead, suggesting recommendations for future research and discussing the implications for clinical practice and music therapy training.

8.1 Some reflections about care work

Various themes around the issues of care work have emerged as a result of this study, with both staff teams making a number of comments, both positive and negative, about their work.

8.1.1 Remuneration in care work

A theme that was prevalent within the two staff teams' transcripts was the idea that the remuneration for care work does not adequately reflect the demands and challenges of the role. Other research studies also concur with this (England, Budig and Folbre, 2002; Palmer and Eveline, 2012). Care work is acknowledged to be poorly paid (Bawden, 2017) and yet the demands of the role are many, requiring highly developed communicative and interpersonal skills:

> ' "Care work is really tough, when you think what these people are expected to do"…"We shouldn't be paying them minimum wages." "Let's make sure more of the money goes to paying care workers, making sure they're properly trained. Paying more would also help to address the perniciously high turnover rates of care staff, leading to better services and reducing recruitment costs." '
>
> (Bawden, 2017)

Within the service where I work, it is the case that care workers have either worked in the same service for very many years, often with little change to the work, or that people come in to care work for a short time, until, for example, they go to college or are in a position to pursue the career they would like to have. It can be very difficult to recruit to care work and, in my experience, group homes are often short-staffed with a

number of unfilled vacancies. An article in *The Guardian* newspaper in 2017 asks why it is difficult to attract younger people to care work. Carolyn Downs, senior lecturer at Lancaster University management school, says that:

> 'One problem with care work specifically is its reputation as a "last resort" career, says Downs. "People say, 'If I can't find anything else, there's always care work'. Although the people who work in care say it's very rewarding, the external view is that it's not rewarding, but demanding… Something identified by Downs' research across Europe is that if care workers had more specialisms and training — for example expertise in diabetes, dementia or visual impairment — it would raise the appeal of it as a career. "The care workers we spoke to want to do specialised training," says Downs. "Even if it wasn't much more money, there's more status." '
>
> (Leach, 2017)

As discussed in §7.4.4, for one of the members of participant F's staff team, an important outcome of this PhD research was that it made her feel valued to be invited take part in research. This highlighted the importance of ensuring that the voices of both adults with learning disabilities and their staff teams are heard.

8.1.2 Time spent in care work and possible correlations to levels of stress and burnout

In the staff teams that participated in this study, it was those that had remained in care work for a long time, regardless of their age, that expressed higher levels of stress and job dissatisfaction. Other authors, such as Gibb, Beautrais and Surgenor (2010), suggest that demographic factors may influence findings about stress levels in care work, but their study suggested that carers that are female, older and more experienced are likely to feel more positively about their work. It has emerged from this PhD research study that staff teams found a combination of supporting someone who self-harms and a lack of supervision and staff meetings stressful. This will be explored further in §8.1.3. Although the more generalised aspects of the stress of the work did sometimes emerge in the SSIs and staff groups it is beyond the remit of this study to measure or analyse that in more depth.

8.1.3 A lack of resources

Within the UK media there is currently widespread reporting of major cuts to health and social services (Busby, 2018; Polianskaya, 2018). Employees of the NHS and social services are being asked to provide services against a background of sustained financial cuts to services. Increased pressures of workloads and demands on time mean that certain resources are becoming very depleted in some services. Locally there have been cuts to arts therapies services within mental health and learning disability services. Within the NHS Trust in which I work, across both our own service and the external care agencies that we work with, there are staff shortages, job vacancies that remain either unfilled or frozen due to a lack of funding, and high levels of staff sickness. Care agencies, providing staff to work in group homes in both the private and public sector, are not always able to provide supervision or training to their staff. It is not uncommon for people to come into care work (for which no previous experience or formal qualifications are required) and receive no training and little or no supervision. As discussed in §5.7, during the first SSI, the team leader of participant F's staff team acknowledged that, due to pressures of time, she had not been able to offer any supervision to her staff team for six months and they had not had any staff meetings for four months. The team leader expressed strong feelings of support for her staff team who, in the second SSI, spoke of how she would send them text messages of appreciation if they had worked beyond their shift pattern. These gestures were appreciated by the staff team and contributed to their feeling valued, but were acknowledged by the team leader as a poor substitute for supervisions and staff meetings. However, a lack of formal, regular supervision in which the challenges of the job could be thought about did appear to correlate to an increased sense of stress for participant F's staff team in particular. This was seen through the SSIs and the monthly staff groups: as a team they found it more difficult to think about some of their more ambivalent and challenging feelings. Although participant B's staff team also found aspects of their role difficult, they did receive regular supervision from their team leader and appeared more comfortable about thinking together about the challenges of the work. Overall, both teams became much more open about expressing a range of

feelings about supporting their service-user when they self-harmed and both reported an increased sense of feeling supported and understood.

I am curious about the particular ways that, for Janet's staff team in particular, the monthly staff groups might have functioned as a substitute for a lack of clinical supervision and staff meetings. It would have been interesting to see if and how Janet's staff team might have used the monthly groups differently, had they existed within the context of regular supervision.

8.1.4 Identifying as a carer

Both staff teams referred to a strong sense of guilt when their service-user self-harmed. Staff members feared being blamed by each other, managers and medical staff attending to their service-user's wounds. In §6.8.2, I described how staff members were quick to follow the expression of any negative feelings about their service-user with comments such as *'we love them really', 'you wouldn't do this job if you didn't care' and 'you certainly don't do this work for the money'.* Both SGFs and myself agreed that it seemed very important for the staff teams to let us know just how much they cared and seemed to identify very strongly with an ideal of what they thought a carer should be. The *Oxford English Dictionary* defines care as 'the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something'. Through the SSIs and the monthly staff groups, the SGFs and I came to think that the staff teams needed to identify with many of the more altruistic aspects of being a carer in order to believe that they were good at their job: staff members often spoke about *'going above and beyond', 'doing my best', 'putting work before family', 'thinking and worrying about service-users in the evening' and 'constantly thinking about how I can make things better.'* Anything that threatened this view of themselves as good carers, in other words more overtly hostile or ambivalent feelings, could not be tolerated and therefore had to be split off and rejected. This invites some important questions about what happens to these split-off feelings if they are not given room to be acknowledged and attended to. I was interested in the potential for a destructive cycle to develop whereby staff members felt hostility towards their service-users when they self-harmed, and

consciously or unconsciously this was conveyed to the service-user, who then internalised this and felt a sense of shame, thus perpetuating the cycle:

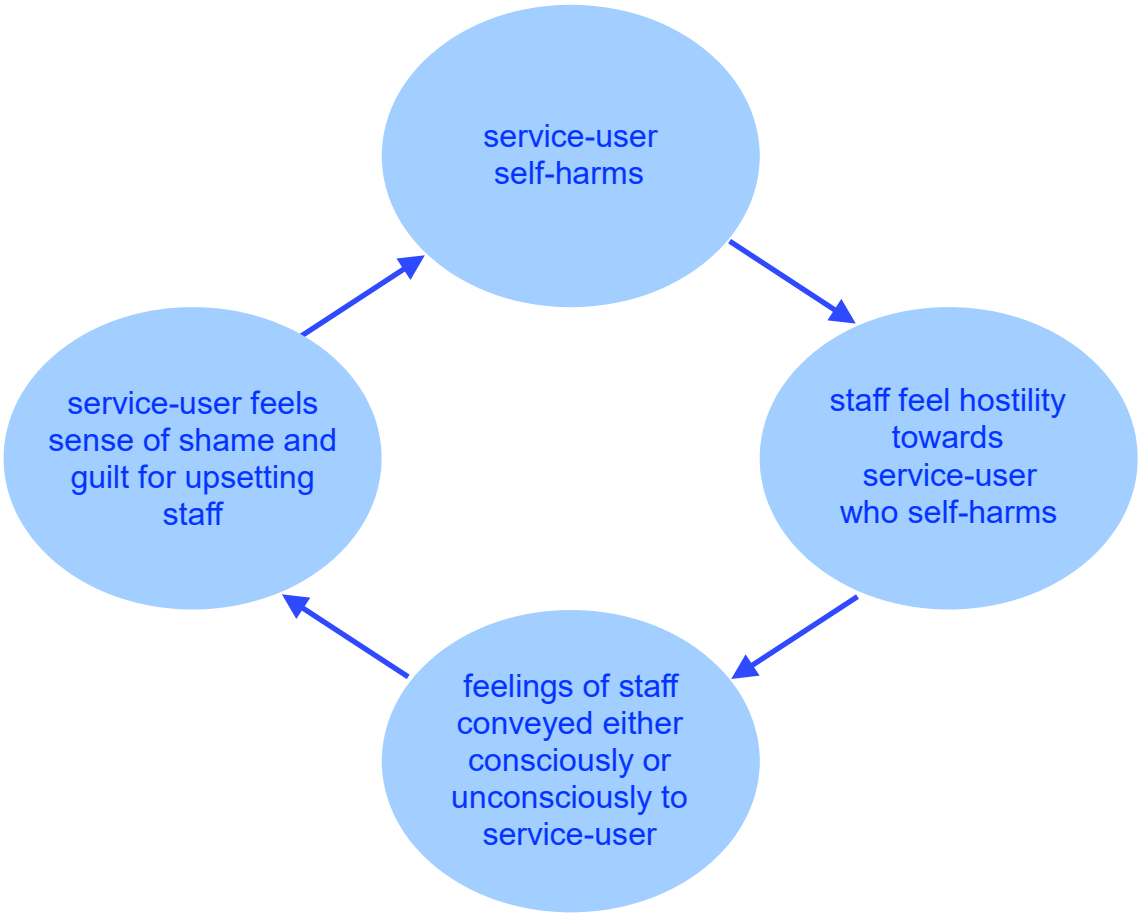


Fig. 8.1: Destructive cycle of self-harming and staff responses

One of the results discussed in §6.5.1 was the dependency that service-users inevitably have upon their staff teams. Issues of power become important when consideration is given to the impulse for the service-user to try to please their staff team for fear of abandonment. There is an example from Janet's transcript (§6.5.1) where she was able to say that when she self-harmed, she felt that her staff team were frustrated with her. She told me she could read this from their facial expressions and it made her feel ashamed. When she felt ashamed and guilty for upsetting the staff she was more likely to self-harm again.

The study showed that, when staff felt they had been attended to and had their frustrations heard, there was less of a need to unconsciously communicate their feelings of frustration and despair to their service-users, thereby, in Janet's case, lessening her sense of shame.

8.2 Some reflections about staff teams

Much has been written about the unconscious processes that occur within institutions and different types of staff groups and teams (Menzies Lyth, 1988; Halton, 1994; Huffington et al., 2004). Halton writes about the ambivalence institutions might feel when they need to seek help:

> 'The consultant who undertakes to explore the nature of the underlying difficulty is likely to be seen as an object of both hope and fear. The conscious hope is that the problem will be brought to the surface, but at the same time, unconsciously, this is the very thing that institutions fear.'
>
> (Halton, 1994, p. 12)

This certainly corresponds to the experiences of myself and the SGFs in this research study: the staff teams were, consciously at least, very committed to attending the groups and finding new ways to understand self-harm and its impact upon their service-user, but unconsciously found ways to avoid thinking about the very difficulties that, on the surface, they wished to address.

When staff teams feel that the service-users they support are receiving therapy or some form of help which they perceive themselves as also needing but not receiving, envious feelings can soon arise:

> 'On occasion difficulties…arise not so much from the desire to be an ideal carer…but from a sense of being an inevitable loser in a competitive struggle… The survival-anxiety of the less successful section stimulates an envious desire to spoil the other's success. This spoiling envy operates like a hidden spanner-in-the-works, either by withholding necessary co-operation or by active sabotage.'
>
> (Halton, 1994, p. 15)

The ideas that Halton expresses here are helpful in terms of thinking about the example in §7.2 where a staff member made an envious remark about his service-user receiving

music therapy. Seen through the lens of Halton's thinking, this remark could suggest that the staff member felt unconsciously engaged in a struggle for survival in which he perceived the service-user as having his needs addressed (through music therapy) whilst he was left to struggle without support.

Menzies Lyth, writing about her research with nurses in a hospital in the late 1950s, observed that:

> 'The work situation arouses very strong and mixed feelings in the nurse: pity, compassion and love; guilt and anxiety; hatred and resentment of the patients who arouse these strong feelings; envy of the care given to the patient.'
>
> (Menzies Lyth, 1988, p. 46)

Some of these conflicting feelings in nursing staff that Menzies Lyth articulates were also observed in the staff teams that participated in this study. When I conducted the first SSIs with the staff teams, both teams described their experiences of struggling in their work. They expressed the feeling of being overwhelmed by their service-user's self-harming and the impact this had on what was already a demanding job. Obholzer and Zagier Roberts (1994) discuss the difficulties for staff in working with people who are in pain, both physical and emotional. They suggest that anxieties generated by the particular nature of the work being undertaken can lead to personal and collective defences, developed to keep the painful nature of the work away from conscious thought. They describe how:

> '…clients rid themselves of their painful feelings, and also communicate aspects of their experience which they cannot put into words, by projecting them into the staff. This can have a profound effect on a staff group. They too can become distressed and deal with this by projection. The whole organisation can then become caught up in the same state of mind as the clients it exists to serve.'
>
> (Obholzer and Zagier Roberts, 1994, p. 49)

This provided a very useful framework for thinking about the two staff groups that participated in this project. The clients, people with learning disabilities who self-harmed, communicated aspects of their experience which they could not put into words into the staff: the pain of disability and of 'not knowing'; frustration; loss. The staff teams, affected by those projections, had themselves become 'not knowing'; unable to

think; frustrated. These feelings, distressing for the staff teams, became projected on to myself and the SGFs, leaving us at times experiencing what it was like to 'not know,' to be unable to think and to feel frustrated. Obholzer and Zagier Roberts (1994) go on to say that, if these complex, unconscious processes can be understood, they can be addressed in helpful ways. This is what the function of the staff teams in this study tried to do: to bring into consciousness some of the defensive responses of the staff teams to their service-users' self-harming; to explore some of the staff teams' ways ofresponding to their service-users and to consider these as unconscious responses to the pain of what they were witnessing when their service-users self-harmed. By giving a voice to the staff teams' unconscious and unwanted feelings, they were able to come to new ways of understanding the complexities of why their service-users self-harmed and to find different, more compassionate ways of responding.

8.3 Reflections on the method

This section will reflect upon aspects of the method, including the method of data analysis and the use of semi-structured interviews for both service-users and staff teams.

8.3.1 Data analysis

A framework of Interpretative Phenomenological Analysis (IPA) was chosen to analyse the data generated through the SSIs. This was discussed in §3.3.6 where it was acknowledged that the use of SSIs is one of the best ways of generating data for an IPA study:

> 'IPA is committed to the detailed examination of the particular case. It wants to know in detail what the experience for *this* person is like, what sense *this* particular person is making of what is happening to them… Data collection is usually (but not necessarily) in the form of semi-structured interviews…'
>
> (Smith, Flowers and Larkin, 2009, p. 3)

In §3.2, §3.3 and §3.4 I have made the case for a small, qualitative study that uses SSIs that were transcribed and then analysed within a framework of IPA. This chosen method was successful because it was the most appropriate way of examining the

personal experiences of the participants in this research study and for identifying commonalities in themes emerging from the analysis. In particular it allowed the participants' experiences to be at the forefront of this research.

8.3.2 Semi-structured interviews

The use of SSIs as a means of gathering information about the experiences of both service-users and staff teams generated rich and detailed data and gave the participants the opportunity to describe their experiences in depth. The advantages and disadvantages of SSIs were discussed at greater length in §3.4.2; in light of that discussion I return briefly to think about the advantages and disadvantages of having conducted the study using this method of generating data.

8.3.2.1 Advantages of the SSI method

The conversational style that the SSIs facilitated allowed the participants to engage with greater freedom, without the pressure of having to generate a correct answer. The delicacy of the subject matter, discussing feelings around self-harming, was better suited to an approach that allowed the experiences of the participants to emerge more gradually and in a way that did not feel overwhelming.

It became clear through the SSIs that staff members carried considerable feelings of guilt about some of their more ambivalent feelings towards their service-users. It was therefore important that a supportive, non-judgemental environment was created in which these feelings could be allowed to emerge. The positive alliance between myself as interviewer and the staff teams was a significant factor in this, as was the alliance between the two SGFs and their respective staff groups. This is supported by an excerpt from participant B's staff team at the end of the final SSI:

'*But I think it's testament to you and* [SGF] *as well, because how you have been with us means how open we've been or how we've been able to take on new information…if you said something and we didn't have any faith in you, it wouldn't mean anything… And we can understand things more and take it on board, and actually feel like we've got a bit of that knowledge as well*.'

8.3.2.2 Disadvantages of the SSI method

The main disadvantage of the SSIs which this study revealed was that the participants could wander away from the topic area, meaning that sometimes material was generated in the transcripts that was not directly comparable. It also meant that considerable time was spent in transcribing material that was not directly relevant to the topic area. On balance, I feel that the disadvantages were outweighed by the advantages of giving time and space to the participants and allowing potential difficult thoughts and feelings to emerge in their own time.

When considering how best to achieve genuine and honest data through the use of SSIs, I was mindful that, for both service-users and participants, describing experiences of self-harming and supporting someone who self-harms might evoke many kinds of uncomfortable feelings. Through both the literature review and my own clinical experience, I was aware of the potential for feelings of shame (Kleinot, 2009; Norris and Maher, 2009) and a desire for secrecy around self-harming and the feelings that might precipitate it. When thinking about secrecy in particular, I was reminded of Winnicott, who said: 'It is joy to be hidden but disaster not to be found' (Winnicott, 1965, p. 186). For the service-users in this study, whilst they may have wanted to hide aspects of their self-harming from their staff teams, the greater wish was to have the reasons for their self-harming understood and validated.

The flexibility of the SSIs as a way of gathering data within a small qualitative study lends itself well to creating an atmosphere where the participants could experience a sense of trust and a feeling that anything they said would be received with interest rather than judgement. This allowed the participants to be open about their experiences, thus helping to generate valid and reliable data.

8.3.2.3 Facilitating reliable data

In terms of taking steps to facilitate the most reliable and honest data possible, it seemed important for potential participants to have a sense of the context of this research study, which included an overview of what is already known about the feelings and experiences of those both engaging in and supporting those that engage in self-harm. When I presented the research study to both staff groups for the first time, I described how other research studies that investigated the experiences of care staff working with people who self-harmed had revealed feelings that included anger, guilt, a sense of being manipulated, burn-out and helplessness among its care staff (Hastings and Remington, 1994; Fish, 2000; Gough and Hawkins, 2000; Thompson, Powis and Carradice, 2008; Heslop and Macauley, 2009; Dick et al., 2010). Understanding that these feelings have already been identified in other staff teams working in this area, and were seen as corresponding to a wider pattern of congruence by researchers working in this area, helped the two staff teams in this research study to feel more able to express their ambivalent feelings more openly. Both teams said they had found it helpful to know that the feelings they had were shared by other people working in the same field.

8.3.3 Limitations of the method

There were some factors that may have weakened the impact of the findings.

- **Sample size:** This study examined the experiences of two service-users and their staff teams. The reasons for selecting a small sample size were discussed in §3.9.1. It would be interesting to develop this research further to see if the findings of this study would be replicated with a slightly larger sample size.

- **Lack of a control group:** In retrospect it may have been useful to have had a control group with which to compare the participants in this study. I wanted to show that the combination of music therapy for the service-users and monthly groups for the staff teams addressed the research questions because everyone was being attended to, but it would have made a different and interesting study if this had been directly compared

to a control group where only the service-user had music therapy and a control group where only the staff team received a monthly group and the service-user was not receiving music therapy. This would allow the different interventions to be considered separately in terms of how they answered the research questions and may have shown whether either music therapy for the service-user or staff groups for the staff teams was the more effective intervention. As it is, the research questions, addressing as they do both the needs of the service-user and the staff teams, suggest a positive correlation between the two interventions offered and an overall improvement in response to the research questions.

- **Timescales:** There were pressures on timescales, particularly in relation to the staff teams. It took considerable effort and organisation for a core membership of the staff teams to be present at the monthly staff groups: rotas had to be organised weeks and sometimes months in advance to ensure that there were enough staff left to carry out the care work whilst the other staff members were attending the groups; sometimes groups had to be organised at times when, in participant B's case, all three residents of the house were occupied with daytime activities or work placements. Although the staff teams were very committed to these monthly groups, participant F's staff team, in particular, expressed concerns about how sustainable commitment to a group of this nature could be in the longer term for staff teams working within a community care model. These issues did occasionally impact upon attendance at the monthly groups because sometimes staff members had to 'cover' work due to other staff shortages within the wider service.

8.3.4 Conflicts in the therapist/researcher role

Boundary complications, as a result of my dual role as interviewer for the SSIs and music therapist for the service-users participating in the study, were mentioned in §3.4.3, where I discussed the issue of the service-users finding it difficult to talk to people they did not know. There is evidence to suggest that a factor that ameliorates against inaccurate or partial responses within semi-structured interviews is the quality of the alliance between interviewer and interviewee (Rubin and Rubin, 2012). When the

participant information sheets were trialled with three users of the local learning disability service who were not going to participate in this research study, one of their concerns was also about participants talking to somebody they did not know, especially about a subject that was personal and possibly difficult to explore. They suggested that this might be addressed by me conducting the SSIs. The conflict of boundaries mainly applied to the service-users and was due to me also acting in the role of music therapist. Since the staff team participants were working with a research assistant in the monthly groups there was less of a conflict of boundaries in terms of me conducting the SSIs for the staff teams. The area where a conflict of role and the possibility of bias were most probable was in my role as conductor of the SSIs for the staff team whilst also being in the dual role of music therapy clinician and conductor of the SSIs for the participants. I tried to reduce the impact of any conflict by ensuring that boundaries of confidentiality were strictly adhered to.

8.3.4.1 Institutional challenges impacting the clinician/researcher role

Had there been the luxury of time and resources, I would have liked to have worked with a psychology assistant in the role of research assistant. With more time to plan and execute the research, a research assistant would have been able to spend time getting to know the participants and building a trusting alliance in preparation for administering the SSIs. This would have been facilitative in generating reliable data whilst also maintaining clearer boundaries within the clinician/researcher role.

Whilst this study was being undertaken, the NHS Trust in which the clinical work was taking place was making substantial cuts to services in an attempt to achieve some financial equilibrium. As part of this process there was a proposal to significantly reduce or possibly terminate the arts therapies service within the learning disability directorate. It was a time of considerable uncertainty across the learning disability service generally; months of uncertainty about the future of jobs meant that an unprecedented number of staff left the service. This created considerable resource issues, some of which had an impact on some of the decisions that needed to be made in terms of conducting this research. The option to recruit research assistants to administer

the SSIs, for example, was not possible due to reduced staffing. An additional consequence of reduced staffing was a lack of students and trainees undertaking placements within the service. This seemed to result from fewer staff needing to undertake larger caseloads and not having the time to supervise a trainee. In the past, arts therapists have worked closely with psychology assistants and that might have been a useful collaboration for this research study.

8.3.4.2 Bias

Researchers write about the importance of understanding bias in phenomenological research in order to:

> 'eliminate everything that represents a prejudgment, setting aside presuppositions, and reaching a transcendental state of freshness and openness, a readiness to see in an unfettered way.'
>
> (Moustakas, 1994, p. 41)

Smith and Noble state that bias is a part of all research and that, whilst the researcher has a responsibility to eliminate bias as far as possible, 'outlining potential sources of bias enables greater critical evaluation of the research findings and conclusions' (Smith and Noble, 2014, p. 100). According to Stan Lester, if bias remains unexamined 'there is an ethical issue about misrepresenting, distorting or deleting findings which have been provided in good faith by participants' (Lester, 1999, p. 3). Bracketing, a way of managing the effects of bias, acknowledges that the researcher may be examining emotionally challenging material and allows that the researcher will have their own responses, beliefs and biases in relation to the research material. Bracketing allows the researcher to find ways of eliminating, as far as possible, their own preconceptions relating to the research, in order that the project can be as authentic as possible:

> 'Bracketing is a method used by some researchers to mitigate the potential deleterious effects of unacknowledged preconceptions related to the research and thereby to increase the rigor of the project.'
>
> (Tufford and Newman, 2010, p. 80)

Self-harm, as acknowledged in the introduction to Chapter 1, is an uncomfortable subject. The participants in this project did not self-harm in my presence, but

nevertheless I found it very difficult to witness the injuries that they inflicted upon themselves, particularly when Derek broke his arm. Although Janet's injuries were usually concealed beneath heavy bandages, Derek's wounds were often highly visible and could evoke both a physical as well as an emotional response in me. When conducting the SSIs with the staff teams, I could feel some empathy for the staff who described feeling repulsed or disturbed by their service-user's self-harming. There was a need to acknowledge and separate my response to the participant's self-harming as experienced as a music therapist within the therapeutic encounter from hearing the staff teams' experiences of their service-user's self-harming within the context of gathering data through the SSIs. My own clinical supervision and personal therapy remained important ways of processing my own responses to this research material and helping to eliminate bias as far as possible. At the recruitment stage, I had made it clear to the participants that, although I would be conducting the SSIs for both them and their staff teams, the confidentiality boundaries between the music therapy sessions and the SSIs for the staff teams would be strictly maintained.

8.3.4.3 Being a clinician-researcher

Yanos and Ziedonis consider the clinician-researcher to be 'an important figure in health research' (Yanos and Ziedonis, 2006, p. 249). The authors identify the potential benefits of being involved in both research and clinical practice, believing that it can facilitate a greater flow of ideas between the two domains. My involvement in these two areas has certainly generated ideas for developing new ways of working therapeutically with people who self-harm and their staff teams. These developments will be discussed in §8.5. Among the more conflictual aspects of the clinician-researcher role, the authors suggest role confusion and ethical considerations, the latter of which the authors describe as the 'interests of the individual participant and the scientific aims of the study' (Yanos and Ziedonis, 2006, p. 251). In this PhD study, the research is investigative, the aim being to investigate and discover rather than to prove any pre-determined scientific aims. Both participants and their staff teams entered the study with a desire for the service-users to find ways of understanding and reducing their self-harming. This was not in conflict with the aim of the study which has been to

investigate whether the use of music therapy and monthly staff groups correlated to this. The greater ethical dilemma in this study has been around confidentiality, which could be understood as role confusion between music therapist and researcher. As explained in §8.3.4, steps were taken at the recruitment stage to address the roles and emphasise the strict adherence to confidentiality.

8.3.5 Carrying out research with adults with learning disabilities

Like everyone, people with learning disabilities have worthwhile things to say and experiences that are worth knowing about and it seems important that researchers find meaningful ways of ensuring that these things are heard. Traditionally there has been relatively little research carried out with people with learning disabilities (Watson, 2007; Durell, 2016). In 2001, Walmsley was investigating the development of conducting research with people with learning disabilities and found that the learning-disabled population 'were tested, counted, observed, analysed, described and frequently pathologised, but never asked for their views' (Walmsley, 2001, p. 188). Various authors attribute this lack of research to the challenges of finding a method that is adequate for this clinical group (Booth and Booth, 1996; Gilbert, 2004; Nind, 2008). Difficulties in communication, rather than being attributed to the participant, might more usefully be considered as existing in the space between researcher and subject and call for particularly creative methods of research. Other authors have raised concerns that people with learning disabilities have too little involvement and control over the research (Aspis, 2000). This was one reason for involving people with learning disabilities in shaping the study design for this PhD research. For her PhD research in 2005, Warner carried out an action research inquiry that investigated the impact of music therapy with adults with learning difficulties and severe challenging behaviour in a group home setting. Central to Warner's research was involving the learning-disabled residents in the research as co-researchers, ensuring that their stories and voices were heard. In common with my research study, Warner's investigation had two components: the co-operative inquiry, which involved home staff, music therapists and day care workers reflecting on the impact, benefits, threats and barriers to the music therapy process, and the music therapy inquiry, where music therapy sessions provided a space

for inquiry between residents, music therapists and day care workers. Warner reported the staff as experiencing burn-out and stress and of finding the work demanding; she made links to how this related to interactions between the staff and the residents:

'Residents were either subjected to aggression or were ignored because members of staff were tired and stretched to the limit.'

(Warner, 2005, p. 82)

By the end of the study Warner had observed that staff had come to new ways of listening to and understanding the communications of residents, stating that:

'the music therapy inquiry enabled staff members to change their perceptions about the residents and about their own relationships with residents.'

(Warner, 2005, p. 365)

8.3.6 Gaining consent

Central to undertaking research that involves the participation of people with learning disabilities is being able to establish the capacity of the participants to consent to being part of the study. This issue has been considered by a number of researchers working in this field (Kellett and Nind, 2001; Cameron and Murphy, 2006; Harris, 2003; Kiernan, 1999). When preparing to submit this study for ethical approval, the challenges of gaining consent from people with learning disabilities to take part in research were significant. Ensuring that participants understood the implications of taking part in the study and made the decision to do so free of coercion or a sense of feeling they needed to please either their staff team or me, required careful consideration. Iacono and Murray (2003) state that there is:

'a need to protect potential vulnerable participant groups, while ensuring that demands placed on researchers are not so restrictive as to preclude valuable research'.

(Iacono and Murray, 2003, p. 49)

Some of these issues have already been considered in §4.3.3, with steps taken to eliminate as many factors as possible that might compromise the findings. These included the use of widgit symbols to ensure that information presented in the

participation information sheets was as relevant and helpful as possible for service-users, and trialling these with non-participatory learning-disabled people.

8.3.7 Self-reporting

A research study like this one requires participants, both service-users and staff teams, to self-report about their experiences around self-harming. I have wanted to ensure that their experiences are heard and are at the heart of this study. There are, however, limitations to self-reporting and these have been documented by Tourangeau and Yan (2007). Among these limitations are the accuracy of self-reporting, especially with regard to the possibility for mis-reporting. They found that mis-reporting was especially prevalent when the topic under investigation was of a sensitive nature and often came about because of the subjects' fearfulness of the implications of what they said within the research context. This has obvious implications for this study and I was mindful that creating a sense of trust between myself as researcher and the participants was an important way to reduce this as far as possible.

In the first SSI, both staff teams seemed concerned with showing themselves to be good and caring staff teams, possibly saying what they thought was the right thing or what they thought I wanted to hear: examples already cited in §6.8.2 included telling me about the strenuous efforts they made to improve life for their service-user. It was only after we had spent some time together during the semi-structured interview setting that other, more ambivalent feelings felt safe enough to emerge. This shows congruence with the findings of Marshall and Rossman (1995) in §3.4.2.1: the strength of the alliance between participants and interviewer is a protective factor against the withholding or mis-representation of data. For the service-users, the pattern was similar: an initial denial of their self-harming giving way to something much more available to think about through music therapy as the therapeutic alliance became more established.

8.4 Contribution of this study to new knowledge

This study has demonstrated that music therapy is likely to make a positive difference to adults with learning disabilities that self-harm. It has also added to the literature about music therapy, adults with learning disabilities, self-harm and the experiences of staff teams. It is the first study to offer a music therapy intervention to a service-user and a simultaneous, separate intervention for the staff team within the field of learning disabilities. Although Agrotou's 1995 PhD study, discussed in §2.3.6 offered a separate group for carers to reflect about the patients and the music therapy process, the carers also had a participatory role in the music therapy groups. The present study has illustrated how self-harm can cause a lot of distress both to the person engaging in it and the staff team who are supporting the service-user. A lack of training, supervision or support exacerbates the difficulty of the staff teams' task. This study has shown that feelings of shame exist for both service-users and staff: for service-users there is the shame of the injury and the subsequent wish to cover it up or deny it; for the staff there is the shame of the ambivalent, at times hateful feelings that they might feel towards their service-users and which they might also try to split off and reject. The service-users in this study have shown how self-harm becomes a valid way of being physically touched and attended to in a world where your staff team adhere to professional boundaries that do not generally allow for hugs and the other expressions of touch that many of us take for granted. The staff teams have provided valuable insights into important aspects of being a carer: the lack of time and resources; the pressures and responsibilities; the poor pay, relative to the demands of the work; the low sense of morale that can be a feature of this work; a sense that nobody can understand the demands of the job and feelings of powerlessness. The fact that both staff teams and service-users made such a strong and positive commitment to this work justified its need.

Since the literature search was finished in December 2017, very few studies have emerged that are relevant to this field. Wells and Dvorak (2018) investigated how music therapy was perceived by the care staff of older adults with learning disabilities. Five direct care staff observed a minimum of one hour of their service-user receiving

music therapy with a student music therapist and were invited to share their experience of this through a SSI. Results showed that care staff found music therapy to be effective in changing physical, emotional, social and cognitive functioning for older people with learning disabilities; care staff were able to use aspects of what they had observed in the music therapy sessions in other activities and staff found pleasure in connecting with service-users through music therapy. This study shares some similarities with this PhD research in its interest in the views of care staff about a music therapy intervention and the conclusion that in both studies the staff perceived music therapy to be beneficial to their service-users. Another study, by Charles and Sanoon (2018), describes a group using both art and music therapy for adults with learning disabilities. The authors discuss their differing modalities and show a progression from alternating music and art therapy groups in a home for adults with learning disabilities to combining the two modalities in response to budget cuts. They make the case for using the two disciplines alongside each other to facilitate new ways for the participants to experience being together creatively. This has relevance for one of the particular developments that has arisen as a direct result of this PhD research; this will be discussed in the next section.

8.5 The impact of the study

Within the NHS Trust in which the clinical work for this research took place, there has been a lot of interest and support for this work. It has highlighted the positive effects of working with staff teams alongside an individual arts therapies intervention for the service-user. As a direct result of this study, colleagues are beginning to use this model of facilitating staff groups alongside any kind of clinical intervention for the service-user. Arts therapies colleagues are becoming increasingly engaged in working with staff teams to support the work that other clinicians in the MDT are doing with service-users and this is being shown to have positive results: staff teams feel better supported; it facilitates a positive relationship between members of the care staff team and members of the MDT; it optimises the intervention for the service-user because it is unaffected by the needs and projections of the staff team and it benefits the service-user if the other agencies involved are working well together.

The results of this study have been disseminated to the two staff teams and the two service-user participants in the form of individual meetings with each. Service-users and staff teams found it positive to know of the significant congruences between themselves and their counterparts and everyone said they had been glad of the opportunity to take part in research that has not been done before. There was a sense of pride in their contributions to new knowledge. This project has also created opportunities to present papers at both national and international conferences, to a BAMT learning disability network meeting and to a number of colleagues in different departments within the NHS Trust. Along with one of the SGFs, I was invited to give a talk to the learning and development team about this project. As a result of that, the learning and development team are looking at ways of involving us in the training of students that undertake placement training within the learning disabilities directorate. This includes both health and social care students and would involve training around how self-harm and other forms of challenging behaviour might be understood and experienced by staff teams and the benefits of arts therapies to learning-disabled people that self-harm. Further opportunities for disseminating this work include a chapter within a book proposal, lectures and a future conference presentation at the European Music Therapy Conference in June 2019.

As a direct result of this research, one of the SGFs and myself have become interested in the possibilities of using art and music with staff teams. We were mindful of how difficult it was for the staff teams in this research study to sometimes engage with some of their more powerful feelings and had wondered about what it might have been like if staff had had instruments and art materials available to them. This was particularly prompted by participant F's staff team, who experienced difficulties in articulating some of their more challenging feelings. I was approached by a colleague to offer some support to a staff team that were managing a household where the residents had a number of interpersonal and health difficulties. One of the SGFs and myself met with them and invited them to consider using art and music as well as talking. The group met six times, once a month. We were very interested to find that this group shared many similar feelings and experiences with the staff teams that took part in this research project. The staff team spoke of very similar difficulties both in their working

conditions and interpersonal relationships. Initially they found it difficult to abandon the familiar currency of speech for something that felt less known and comfortable. After these initial reservations the staff became very interested in the opportunities that music and art making afforded. They photographed their work at the end of each group and the music was recorded. They took ownership of what they created and were proud of it. They came to new ways of thinking about what was happening in the house where they worked and seemed to make a connection between this and being offered a new way to be creative together. We have produced a short film about this work with the consent of the participants in the group and hope to develop this way of working with other staff teams within our service.

8.6 Future research

This study has identified that, although there has been some work that considers music therapy with learning-disabled adults that self-harm, it is a small body of work. There is a more substantial amount of work that investigates the impact on staff teams of supporting people with learning disabilities that self-harm and these studies have made recommendations for the type of support that staff teams have asked for. This study has tried to respond to those recommendations, whilst offering a simultaneous music therapy intervention for the service-user. I believe this to be the first study to do this. Given the prevalence of self-harm, the impact it has and the challenges that it brings, I hope that this research study contributes to greater dialogue and debate about how music therapy might contribute in this area.

Further research in this area would be a welcome addition to the literature. As discussed in §8.3.3, I would like to develop my own research in the use of music therapy with learning-disabled adults who self-harm by repeating this work with a larger sample size and using control groups to help isolate which part of the dual intervention was more effective in reducing the frequency of the self-harm.

I am also interesting in developing music therapy work with staff teams and carers that support adults with learning disabilities (regardless of whether or not their service-user

self-harms). Undertaking this research has highlighted the demands placed upon staff teams and the ways in which the needs of staff teams interact with those of service-users, especially when staff teams perceive their own needs as unacknowledged and unmet. The potential for staff teams to unconsciously sabotage their service-users' therapy because of an envious wish for their own, demonstrated by the example given in §7.2, highlights the need for further research into how the needs of staff teams can be addressed.

Another spin-off from this research is an interest in offering music therapy to parents of a person with a learning disability. One of the SGFs and myself are working on an idea for a further research project which would look at offering music therapy to the service-user alongside a separate, individual music therapy intervention to carers, which may include a parent of a person with a learning disability. As well as staff teams, we are aware of parents who find their dual role as parent and carer challenging and would welcome a therapy space in their own right and with their own therapist.

8.7 Implications for clinical practice

This study has highlighted gaps in provision for clinical practice and has generated some ideas about what might be helpful for care staff. Within social care there are inconsistencies in the ways in which staff teams receive training about how to support people with learning disabilities that self-harm. In my experience, this training is often lacking altogether and staff are 'thrown in at the deep end' and expected to know what to do when somebody they are supporting self-harms. This places unrealistic expectations on people who might be new to care work and can contribute to unhelpful divisions between care staff teams and members of the MDT to whom the service-user might be referred. In our service we are often aware of an expectation from the staff team that the clinicians in the MDT are 'the experts' and are going to provide the staff team with the answers they require. This creates a more uncomfortable thought: if the staff teams see members of the MDT as the experts, how do they think of themselves? Whilst the clinicians in the MDT might have specific clinical knowledge, it is often the staff team that knows the service-user best and has the most experience of supporting

them on a day to day basis. As this study has shown, staff teams often feel undervalued and can sometimes both want the help that the MDT might be able to offer, whilst also resenting the fact that the situation might feel overwhelming and be beyond what they feel able to manage. A more realistic and balanced view might be that there are no experts, but rather people that are open to thinking together and bringing their experiences to bear in the service of finding a creative way forward.

8.7.1 Music therapy training

Music therapy students are likely to be used to spending time together in groups. Most notable of these perhaps is the experiential group, where students will encounter some of the unconscious processes that happen when a group comes together without a fixed agenda. It is beyond the scope of this study to know or discuss the emphasis on group and institutional dynamics that different music therapy trainings might have, but I feel there is some validity to music therapy students having some training about some of the defences, projections and feelings of envy that might exist for care staff. As this study has shown, these unconscious dynamics can have significant effects upon the music therapy encounter for the service-user. For music therapy students, seeing patients for the first time and setting up sessions, I think it could be very valuable to have had some training about some of these unconscious processes that might impinge on the framework around their clinical encounters.

Menzies Lyth, describing her work with nurses in a hospital, discusses some of the more conflictual feelings that both patients and relatives might experience towards nursing staff. These complex and competing feelings can also be experienced by staff teams and service-users, as this study has shown. Menzies Lyth states that:

> '…patients often resent their dependence; accept grudgingly the discipline imposed by treatment and hospital routine; envy nurses their health and skills… Relatives may also be demanding and critical, the more so because they resent the feeling that hospitalisation implies inadequacies in themselves. They envy nurses their skill and jealously resent the nurse's intimate contact with "their" patient.'
>
> (Menzies Lyth, 1988, p. 48)

As music therapists, we might work with people who are not able to access music therapy independently, needing to rely on a family member or a member of care staff to support them to access the sessions. This does potentially allow for some complex dynamics to occur. Our intervention for 'their' service-user may be both welcomed and resented, as Menzies Lyth suggests: it perhaps unconsciously implies that, by seeking music therapy, the family member or carer is having to acknowledge that their relative or service-user is experiencing something beyond what they as carers/parents can understand and attend to.

This study has highlighted some of the feelings encountered by staff teams supporting someone with a learning disability who self-harms. A spin-off from this research, an art and music therapy group with a staff team discussed in §8.5, suggests that staff teams working in learning disability services can make use of an arts therapies intervention in their own right. It would be a welcome development for this idea to be considered in music therapy training courses, thereby equipping future music therapists to extend their thinking to staff teams and carers/parents as well as to their patients.

8.8 Final thoughts

This study has contributed to the knowledge about music therapy and people with learning disabilities that self-harm and the staff teams that support them. It has given a voice to learning-disabled adults and staff teams that are often neglected and undervalued. I give the final thought to the participants that took part in this study:

Participant F: '*When I play music it gets my feelings out and makes me feel happy and good inside*.'

Participant B's staff team: '*I think music therapy has been really, really helpful. Before this, Derek used to keep everything really bottled up…kind of…he would not say anything, then "argh" there would be an explosion and he would go from seeming OK to self-harming. Now he talks more, and I think that's because he's had the space to express himself with you. It's definitely made a big difference*.'

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A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language*

easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.

This qualitative first person research study will be with adults with mild-moderate learning disabilities, who regularly self-harm. The study will last for one year. I will investigate the combined approach of weekly music therapy sessions for the service user, with its opportunities for musical and non-verbal therapeutic engagement, alongside a monthly staff support group for the care staff who are supporting the service users. Also investigated will be an analysis of changes in the staff's perception and response to the self-harming. Links will be explored between any reduction in the incidents of self-harm and changes in staff perception during this period. It is recognized that staff teams trying to support such service users often experience feelings of guilt, anger and hopelessness. An article published in 2010 in the Journal of the British Institute of Learning Disabilities, looked at staff beliefs about why people with learning disabilities self-harm. They identified five viewpoints which demonstrate a range of beliefs held by staff. Their perceptions of self-harm were shown to effect the quality of care offered to service users. The conclusions from the BILD study are that staff would welcome further support and would like to be better able to understand the complexities arising from supporting such service users. A means of expressing the tensions arising from supporting such service users is also one of the recommendations. By offering a staff support group alongside weekly music therapy for the service user, I wish to see whether this combined approach that attends to the staff team as well can be linked to any reduction in self- harm. There will be semi-structured interviews with service users and staff prior to the start of music therapy treatment, and measurements will be made to determine the frequency of self-harming throughout the study.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

This study involves research with adults with learning disabilities and the staff teams that support these service users. In order for such service users to consent to taking part in this study it would be essential to produce an information leaflet that clearly outlines the nature of the study and what participation would mean for the service users and staff teams in language and terms that would be meaningful and understandable by the participants. Participating service users would be in the mild learning disabilities range who, in accordance with the Mental Capacity Act would be assumed to have capacity to consent to involvement in this study. Capacity to consent to being in the study will be re-assessed within each music therapy session by making sure participants understand what being in the study means, can recall the information, weigh it up to make a decision and convey by any means a decision whether or not to continue participating. The researcher has consulted with speech and language therapy colleagues to best ensure that information leaflets are easily understandable, and provide information in a format that enables invited participants to make an informed choice about taking part in the study.

There are no significant ethical or management issues arising from this research. It is a first person, single-case design. Participation in the research will not change the treatment pattern that would be offered to service users.

My role in this study will be as both clinician (music therapist undertaking clinical work with service users) and also researcher, analysing the data arising from the semi-structured interviews and interpreting the results of the research. Another music therapist from our team will undertake the monthly support groups and semi-structured interviews with the staff teams.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

○ Yes - proportionate review ◉ No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply*:

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☑ Qualitative research
- ☑ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

Does the combined approach of weekly music therapy for the service user with learning disabilities who self-harms, alongside a monthly staff support group coincide with a reduction in the number of incidences of self-harm?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

Does staff attitude change in relation to supporting adults with learning disabilities who self-harm as a result of a combination of individual music therapy being delivered to their service user/s and regular staff groups for themselves? Does staff understanding about the nature and impact of self-harm increase?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

This research acknowledges the challenges and complexities for staff teams who support service users with learning disabilities who self-harm. There is much research to suggest that how a staff member feels at any given time in relation to the patient can influence the way the staff member responds to an incident of self-harm. Snow E., Langdon P. and Reynolds S. (Journal of Learning Disabilities 2007) state that cognitive-behavioural theorists attempting to understand staff response to self-harm suggest that the behaviour of care staff is determined by their emotional responses and their beliefs and perceptions about self-harm. Thompson Andrew R, Powis J and Carredine A (International Journal of Mental Health Nursing June 2008) also conclude that the quality of care that people engaging in self-harm receive is likely to depend on how staff understand the behaviour and their own reactions towards it. Both studies agree that literature searches in the area of self-harm reveal very few studies relating to the experience of health care professionals and that the existing literature tends to concentrate on the experiences of A&E staff and those working in medical settings. A staff support group that acknowledges the staff's feelings and concerns and can discuss the ways in which the service user's behaviour impacts upon the staff team can come to new ways of understanding self-harm and its meaning. My research study therefore investigates a gap in knowledge about how staff's understanding of self-harm influences their response to the service user and in particular what meaningful support can be offered to staff to enhance understanding and support improved relationships between service users and support staff. Fish R. (2000) investigated experiences of care staff working with patients who self-harm within a forensic learning disability service and concluded that staff felt relationships with patients were sometimes hostile and involved issues of power struggles, boundaries, risk and control. Many of these studies make recommendations for further research into ways of supporting staff teams and say that staff teams would like better information about the nature of self-harm and how to respond to it. (See reference to the British Institute of Learning Disabilities study referred to in section A6-1) The weekly music therapy individual intervention for the service user offers a non verbal, psychotherapeutic encounter in which feelings can be expressed and acknowledged through improvised musical exchanges. Through this medium the therapist seeks to understand something of the service user's unconscious emotional world. Reasons for self-harm can be explored within a safe and supportive therapeutic environment. An

extensive literature search has found no current research into the effects of music therapy on adults with learning disabilities who self-harm. There are many articles about self-harm in people with learning disabilities. Brown, in Cutting to Live - A Phenomenology of self-harm, published in the Journal of Marital and Family Therapy (2012) states that "despite growing prevalence rates, researchers have yet to adequately address the treatment needs of those engaging in the (self-harming) behaviour. Relatively no data are available regarding empirically based preventions or interventions (Prinstein 2008) and no empirically supported treatments are available to reduce self-harming behaviour."

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

This is a small, qualitative, single case design study involving between 3 and 5 adults with learning disabilities who self harm plus a group of up to 8 care staff for each service user. The research design includes semi-structured interviews with both service users and care staff separately. The referral process will follow the usual protocol for assessment and treatment. In this service, music therapy is one of many interventions offered by the multidisciplinary health and social care team to adults with learning disabilities. There are 5 teams in geographical areas within the [redacted] and I work in the [redacted] team. Any member of the health and social care team can refer to music therapy or indeed any other discipline within the team. Once ethical approval has been obtained for this study, I would visit each of the 5 teams to outline the study and invite clinicians to identify and refer to the study any service users and their staff teams who fulfil the relevant criteria. Upon receipt of a referral of a service user to this study, the referrer and myself will write to the service user and the care staff team inviting the service user and a representative of the care staff team to meet with us. This meeting would happen where the service user feels most comfortable, either in their own home or in a quiet meeting room in the [redacted] team department where the research will take place. This initial meeting will allow the referrer to introduce me to the service user and staff member, and will involve a discussion about the study and what participation would involve. An introductory leaflet will be left with the service user with an invitation to find out more in the participant information sheet. If the service user wishes to find out further information at that point, I will present the service user and staff member with separate participant information sheets outlining in detail what their participation in the study would involve. These can either be discussed at this meeting or left with the service user and staff member to discuss with the rest of the staff team in their own time. A subsequent meeting will be offered, if required, to discuss any further questions that potential participants may have. The service user will be invited to attend weekly music therapy sessions with me for 45 minutes at the same time each week for one year. Sessions will be held at the team base which is in a small community NHS hospital. During music therapy the service user and myself will think together about the things that make the service user want to harm themselves. Music therapy offers verbal and musical expression of complex emotional states within a supportive therapeutic relationship. It offers the chance to process trauma and to find ways of understanding one's feelings and responses. The music therapy sessions will be recorded for the purposes of analysing the results. The semi-structured interviews will offer a way of measuring the frequency of self-harming incidents throughout the study. If the service user consents to this, they will be asked to complete a consent form (attached). The staff group who support the service user will be invited to attend a group meeting once a month for one year. This will be run by a music therapist from a different team within the [redacted] The groups will offer the staff teams a space to think and talk about the needs of the service user they support, how caring for someone who self harms affects them both individually and as a staff team and how they understand self harm and respond to it e.g., do they each have a different approach or do they have a team approach which all staff follow? Once consent has been given, each member of the care staff teams will be asked to sign a consent form. There will be an initial interview with the service user, and separately, with the staff team. These will be semi-structured interviews, consisting of a set of separate questions for both service users and staff teams(attached) which will be repeated half way through the study and at the end. These interviews will happen in a room within the learning disability team's department, where the individual music therapy sessions and staff groups will also take place, in designated rooms. The questionnaire will ask about the frequency of self-harming incidents; it will also ask about the service users's current emotional state and what the service user would like to change. The service user's individual weekly music therapy, will commence for one year. At the same time the staff team will be asked about how they understand the service user's self harming and about their own responses to it.(separate specifically designed questionnaires). They will be asked about their experiences of supporting a service user with a learning disability who self harms, and what the impacts are upon them individually and as a staff team. Finally, the staff questionnaire will ask what the staff team would like to change and what they might find helpful from the monthly staff group meeting.The questionnaires will be repeated 6 months into the study and again at the end. The writing up of this research study will form my thesis.
If either of these interventions is deemed still appropriate after that time, it can be continued outside of the research study.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- [x] Design of the research
- [x] Management of the research
- [x] Undertaking the research
- [x] Analysis of results
- [ ] Dissemination of findings
- [ ] None of the above

Give details of involvement, or if none please justify the absence of involvement.
Within any psychotherapeutic treatment, the process is guided by the therapeutic encounter between service user and therapist. Part of the design includes case studies of clinical sessions. Patients will be included in decisions about how the therapy takes place. During therapy patients are offered the opportunity to express emotional states (musically or vebally), that may feel unbearable and overwhelming,in a safe, non-judgmental way environment. This process is determined by the preoccupations of the patient. In this way, users are continuously part of this qualitative study. Similarly staff teams will guid the goup meetings by determining the agenda themselves and using the group to think about particular difficulties they encounter in supporting their patient.The questionnaires will be piloted with other carers/staff in the service, prior to the actual implementation.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research

Select all that apply:

- [ ] Blood
- [ ] Cancer
- [ ] Cardiovascular
- [ ] Congenital Disorders
- [ ] Dementias and Neurodegenerative Diseases
- [ ] Diabetes
- [ ] Ear
- [ ] Eye
- [ ] Generic Health Relevance
- [ ] Infection
- [ ] Inflammatory and Immune System
- [ ] Injuries and Accidents
- [x] Mental Health
- [ ] Metabolic and Endocrine
- [ ] Musculoskeletal
- [ ] Neurological
- [ ] Oral and Gastrointestinal
- [ ] Paediatrics
- [ ] Renal and Urogenital
- [ ] Reproductive Health and Childbirth
- [ ] Respiratory
- [ ] Skin
- [ ] Stroke

Gender:	Male and female participants
Lower age limit: 19	Years
Upper age limit: 65	Years

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

The participants will be men and women between the ages of 19-65 years with mild learning disabilities who self-harm and who have capacity to understand the questionnaires and what participation in the research would involve. Also included in the study will be the staff teams who support these service users. These will be staff members who have daily or regular contact with the service user.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Service users who have had music therapy before.
Service users who do not have capacity to understand the questionnaires and consent to being in the study.
Service users without learning disabilities.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Seeking consent to participate in the research.	1-2	1-2	45 minutes	Consent will be sought from the service user and their staff team. This meeting will be conducted by the music therapist researcher and will be offered in the service user's own home or in a quiet room at the learning disability team department, according to the service user's and staff team's preference.
Semi structured interviews using questionnaires for service users and staff at the start, middle and end of the study.	3	2	20-30 minutes	The questionnaires will ask 7 questions aimed at measuring changes taking place over the course of treatment. These interviews will take place at the learning disability team department.

A21. How long do you expect each participant to be in the study in total?

18 months

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

◉ Yes ○ No

If Yes, please give details of procedures in place to deal with these issues:

It is always possible during therapy that difficult disclosures will be made. Both service users and staff teams will be made aware before the start of the study that any such disclosures will be treated according to their nature, and may require intervention from other agencies external to the study if the service user, staff or others are thought to be at risk. This is usual clinical practice. If other agencies need to be informed on a need to know basis, then the confidentiality which will govern this study may not be able to be strictly adhered to. This will be made clear to all participants prior to the start of the study.

A24. What is the potential for benefit to research participants?

The potential benefit to service users is a reduction in self-harm, greater capacity for emotional reflection and interpersonal relationships and an improvement in their relationships with the staff teams who support them.

For staff teams the potential benefits are an improved understanding of caring for a service user who self harms and of the ways in which this impacts upon them individually and as staff team. Such insights allow for changes in how the staff respond to the service user during an episode of self-harm.

A26. What are the potential risks for the researchers themselves? *(if any)*

There are always potential risks to therapists in terms of lone working with vulnerable service users with complex mental health needs in a therapeutic environment. Very occasionally an act of violence or aggression may occur towards the therapist. The therapy sessions, and indeed staff support groups will take place in the learning disability team department where there will be other clinicians around at all times. The therapy treatment room is equipped with a panic button. The therapist researcher in this study will receive regular clinical and research supervision, and has 18 years experience in this field and a good understanding of how to minimise any risks in the work.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe your recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants' records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of social care or GP records, or review of medical records. Indicate whether this will be done by the direct care team or by researchers acting under arrangements with the responsible care organisation(s).*

Potential referrals to this research study will be via other health and social care professionals working in the same team as the researcher. It is anticipated that as researcher, I will be outlining this study to my colleagues and inviting them to consider service users and staff teams within our service who might meet the relevant criteria. Once potential participants have been identified, I will review the medical records(health files) held within the team department to further ascertain the suitability of the service user to the study.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

◉ Yes ○ No

Please give details below:

Identification of potential research participants will involve accessing health information kept in medical files and held within our department. See A27-1

A27-3. Describe what measures will be taken to ensure there is no breach of any duty of confidentiality owed to

A27-3. Describe what measures will be taken to ensure there is no breach of any duty of confidentiality owed to patients, service users or any other person in the process of identifying potential participants. *Indicate what steps have been or will be taken to inform patients and service users of the potential use of their records for this purpose. Describe the arrangements to ensure that the wishes of patients and service users regarding access to their records are respected. Please consult the guidance notes on this topic.*

Within the department, all service user health files are kept in locked filing cabinets to which all health and social care professional staff have access. Specific service user's files will only be accessed in the event of a service user being referred to the study by a colleague. Such access will be within the clinical and information governance guidelines of the [redacted] NHS Trust. I am fully compliant with the Trust's mandatory training in information and clinical governance.

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?

○ Yes ◉ No

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes ◉ No

A29. How and by whom will potential participants first be approached?

Referrals of service users to the study will come through clinicians in the multi-disciplinary health and social care team. Initial discussions between referrer and music therapist researcher will take place. If the referral seems appropriate the referrer and researcher will meet with the service user to outline the research project. At this point the service user will be given the service user invitation letter (see attached) If the service user is receptive to finding out further information, they will be offered a participant information leaflet (see attached) which can be discussed at that point if the service user wishes. Alternatively the participant information leaflet can be left with the service user for their consideration and a further meeting offered if the service user has subsequent questions.

A30-1. Will you obtain informed consent from, or on behalf of, research participants?

◉ Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

The therapist researcher will be seeking consent from adults with mild to moderate learning disabilities and their staff teams. A written information sheet will be produced in consultation with a speech therapist colleague. All service users participating in this research will fall within the mild - moderate learning disability range and will therefore in accordance with the Mental Capacity Act be assumed to have capacity to consent or not to their involvement in this study. Consent will be continually assessed via the weekly music therapy sessions.

If you are not obtaining consent, please explain why not.

n/a

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

◉ Yes ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

Service users and staff teams will be given 7 days to decide whether or not to take part in this research.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?*(e.g. translation, use of interpreters)*

Participant information sheets will be produced with a speech and language therapist and will involve the use of symbols as well as language to enable the information to be as accessible as possible. Verbal explanations will acknowledge the service user's diagnosis of mild learning disability and their use of receptive and spoken language. All participants will be verbal and will be assumed to have the capacity to consent or dissent.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

- ○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ◉ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ○ The participant would continue to be included in the study.
- ○ Not applicable – informed consent will not be sought from any participants in this research.
- ○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data in the sense of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?*(Tick as appropriate)*

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Access to social care records by those outside the direct social care team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☐ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☐ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☑ Use of audio/visual recording devices
- ☐ Storage of personal data on any of the following:
  - ☐ Manual files (includes paper or film)
  - ☑ NHS computers
  - ☐ Social Care Service computers
  - ☐ Home or other personal computers

- [ ] University computers
- [ ] Private company computers
- [ ] Laptop computers

Further details:
Both music therapy and staff team sessions, as well as all semi-structured interviews will be audio recorded for the purposes of analysis of the results. All recordings will be coded and anonymised.

A37. Please describe the physical security arrangements for storage of personal data during the study?

All personal data including audio recordings will be stored in a lockable filing cabinet in the researcher's office. The key to this filing cabinet will be locked in a key cupboard within the department to which only the researcher has access. This will be on NHS property.

A38. How will you ensure the confidentiality of personal data?*Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

All personal data will be anonymized and encrypted except for clinical entries in the service user's health files, where all health interventions are recorded within the clinical team regardless of inclusion in research. The music therapist researcher will maintain separate notes about things of significance to the research study in the therapy session and staff support meetings, and these will be encrypted and stored separately to the link data.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

For clinical work all members of the multi-disciplinary team have access to the health files of all learning disabled people known to our team, within the geographical area that our team covers. Clinical notes pertaining to the service user's weekly music therapy sessions will be kept in these health files, according to team and Trust policy and can be accessed by other clinicians within the team. All data pertaining to the study will be accessed only by the music therapist researcher and will be stored as described in A37/38 and then encrypted/anonymised. Academic supervisors will later have access to this according to the level agreed in the consent.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

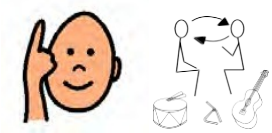
The data will be analyzed both at the library facility of Anglia Ruskin University, Cambridge and at the NHS site where the research is taking place. All data will be stored in a lockable portable storage device for secure transportation of data between these two sites to which only the researcher will have access.

Appendix B: Participant Information Sheets and Consent Form with Widgit Symbols for Service-Users

Initial invitation letter

Music Therapy, Learning Disability and Self Harm

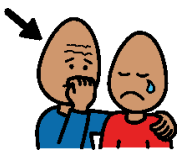
I would like to invite you to take part in a study.



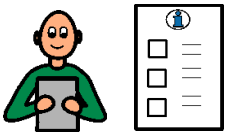
I want to understand more about music therapy

for people with learning disabilities

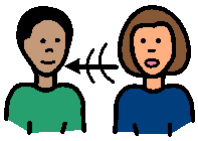
who hurt themselves when they feel unhappy.



I also want to learn about how the staff teams look after people who have hurt themselves.

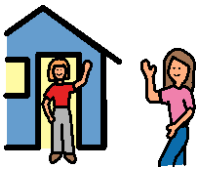


You can find out more in the information sheet.

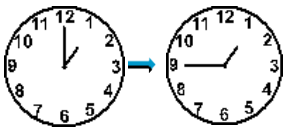


If you want to know more

you can meet me to talk about it



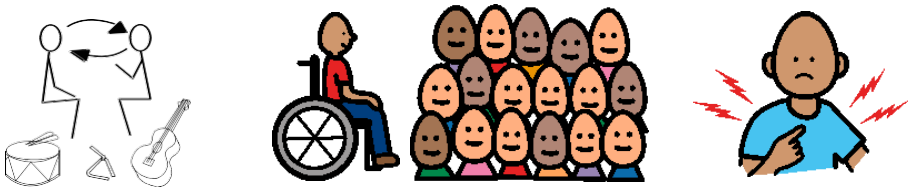
or I can visit you at home.



This will take about 45 minutes

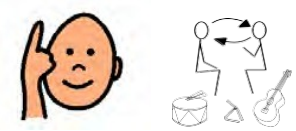
Thank you.

Hayley Hind
Senior Music Therapist and Researcher



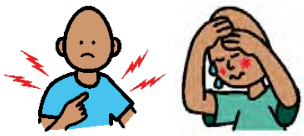
Music Therapy, Learning Disability and Self-harm

Information Sheet

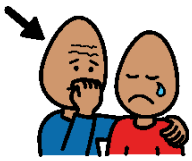


I want to understand more about music therapy

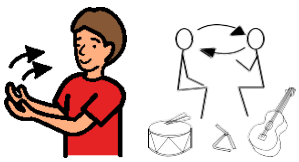
for people with learning disabilities



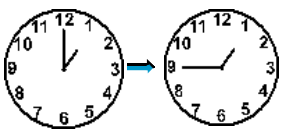
who hurt themselves when they feel unhappy.



I also want to learn about how the staff teams look after people who have hurt themselves.



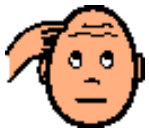
I would like you to come to music therapy



for 45 minutes at the same time each week

1 

for one year.

In music therapy we can think about

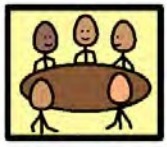

the things that make you feel sad and worried


and might make you want to hurt yourself.

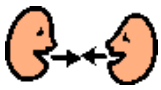

We can play musical instruments.

We can listen to music.

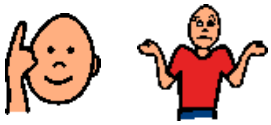
The staff who support you



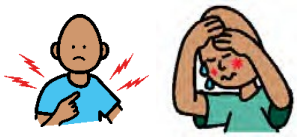
will go to a different group.



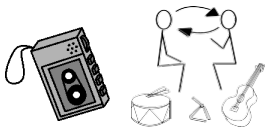
It will help them



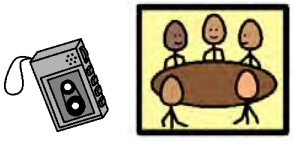
understand why sometimes you hurt yourself



when you are feeling upset or worried.

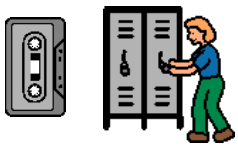


I would like to audio record your music therapy



and the staff groups.

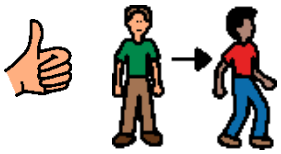
I would like to look at your health records.



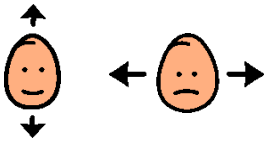
All audio recordings will be confidential and locked away safely.

The research may help you and other people.

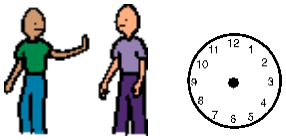
Taking part in the study will not harm you.



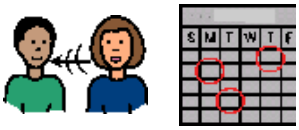
You don’t have to take part.



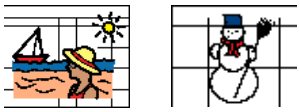
You can say yes or no.



You can stop any time you want to.



I would like to speak to you at three different times.



Each visit will be six months apart.

When the study is over, I would like to write about the work and speak about it so that other people can learn from it.

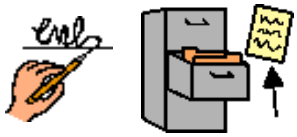
Your name will be changed, so that nobody will know you took part in the study.

Do you have any questions?

You may like to think about it for a few days.

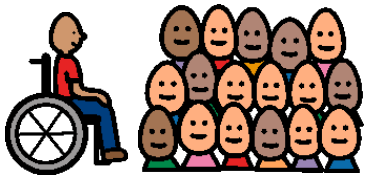
We can meet again to talk about any questions you have.

If you do agree to take part

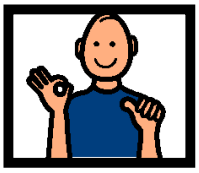


you will be asked to sign a form to say you agree to this.

Thank you.

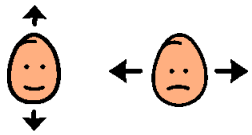




Music Therapy, Learning Disability and Self-harm



Consent Form

I agree that:



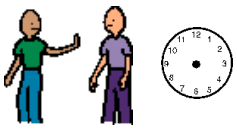
	Yes	No
You can see me for music therapy	☐	☐
You can talk to me about things that make me feel sad or worried	☐	☐
You can audio record the music therapy session	☐	☐
You can look at my records	☐	☐
You can speak to me at three different times	☐	☐
You can write about the study	☐	☐
You can tell others about the study	☐	☐

I understand:

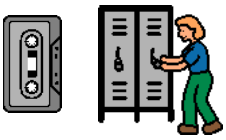
yes

no

What taking part involves ☐ ☐



That I can stop taking part at any time ☐ ☐



That the recordings will be kept safely locked away ☐ ☐

I agree to take part ☐ ☐

Name: ……..

Date: ……..

Witness' Name: ……..

Relationship to service user: ……

Date: ……

Person taking consent (Researcher)

Name: ……

Date: ……

Copies to: Service users
Carer
Researcher
Health records

Hayley Hind
Senior Music Therapist and Researcher

Appendix C: Participant Information Sheet and Consent Form for Staff Teams

Information sheet

Participant Information Sheet – Carer Version

Music Therapy, Learning Disability and Self-Harm

I would like to invite you to take part in a research study. To help you decide if you would like to take part, it is important that you understand why the research is being done and what it would involve for you if you decide to participate. You will have an opportunity to go through the information sheet with me and to ask any questions you might have. This will take around 45 minutes.

What is the purpose of the study?

This study is looking at the effects of music therapy for people with learning disabilities who self-harm and also how staff teams support these service users. We know that self-harm presents significant challenges for both staff and service users. It can often be difficult to understand the meaning of an act of self-harm and to know how to respond to it. The study will look at a combined approach of individual weekly music therapy for the service user alongside a monthly (non-music) group for the staff team over a one year period. The study will look at any possible link between the combined approach of individual music therapy for the service user and a monthly group for staff and a reduction in the incidences of self-harm.

Who is organising the research?

The research is being organised and conducted by Hayley Hind, Senior Music Therapist and Researcher, in fulfilment of a PhD. The research is part of a collaboration between [redacted] and Anglia Ruskin University, Cambridge.

Why have I been invited to participate?

You are being invited to participate because you support somebody with a learning disability who self-harms. It is anticipated that there will be between 3 and 5 service users and their staff teams participating in this research and it is essential for the purposes of the study that both the service user and their staff team agree to take part.

Do I have to take part?

It is your decision to join the study. The research will be described to you and I will go through the information sheet with you. If you decide to take part, you will be asked to sign a consent form. You are free to withdraw from the study at any time, without giving a reason. This would not affect the standard of service you receive. If you withdraw from the study, any information you have given will be destroyed.

What will happen to me if I choose to participate?

If you choose to participate in this study two things will happen. Firstly, you will be asked to meet with me for an interview. This should take approximately 30 minutes. I will ask you about how often the service user you support currently self-harms, your understanding about these acts of self-harm (including why you think the person does it and how they might be feeling), and how you and other members of the staff team respond when the service user you support self-harms. These interviews will be repeated twice more at six monthly intervals and the same questions will be asked each time.
Secondly, you will be asked to be part of a staff group that will meet 12 times at monthly intervals over a year. In these groups you will be invited to think about:

- the needs of the person you support
- how caring for somebody who self-harms affects you, both individually and as a staff team
- different ways of understanding what an act of self-harm might mean for the service user
- your hopes and expectations for the outcome of this work

Each group will last for one hour and will be held at [redacted]

I would like to audio record the interviews and the groups.

Are there any possible risks to taking part?

I do not think there are any risks attached to participating in this study.

What are the potential benefits to taking part?

I cannot guarantee the outcomes of this study. However, it is expected that the study may raise awareness of supporting people with learning disabilities who self-harm, and will provide extra support to yourself and your staff team through the groups. It may also increase knowledge about music therapy and its potential benefits for this group of service users. I am very interested in your views and the findings from this study will be used to improve services locally and if possible, nationally.

Will the information be kept confidential?

All data will be kept confidential and locked away at the [redacted], for use only by the researcher and members of the supervisory team. The interviews, staff groups and music therapy sessions will be audio recorded and securely transferred to a computer. The data will be destroyed after 3 years from the end of the study.

Where can I obtain more information?

If you require further information or have any questions relating to this study you can contact Hayley Hind, (researcher) on [redacted]

What should I do if there is a problem?

If you have any concerns about this study and would like to speak to somebody independent of the researcher, please contact the Patient Advice and Liaison Service (PALS) on [redacted] They are able to help resolve concerns if you wish to make a complaint.

Thank You

Consent form

Participant Consent Form – Carer Version

Music Therapy, Learning Disability and Self-Harm

Please initial in the boxes on the right	Box
• I have read and understood the Information Sheet about this study. I have had an opportunity to discuss it with the researcher and ask any questions. I have had these answered to my satisfaction.	☐
• I agree to be interviewed at three points during the study.	☐
• I agree to take part in 12 monthly support groups for staff.	☐
• I agree to the interviews and support groups being audio recorded.	☐
• I understand that I can withdraw from the study at any point without giving a reason and that the service I receive will not be affected.	☐
• I agree to the publication of this research for academic purposes. I understand that all names will be changed to protect anonymity.	☐
• I consent to taking part in this study.	☐

Signature of Participant: .....

Relationship to Service User: .....

Person taking Consent (Researcher): .....

Date: ….....

Copies to: Participant
Researcher
Service User's Health file

Consent Form – Carer Version
Version 5 11/5/14

Appendix D: Collating the Responses to the SSIs

This section shows how I collated the responses to the SSIs for both participants and staff teams. As part of the data analysis, I looked at each of the SSI questions asked of both service-users and staff teams and compared the responses across the three SSIs. I have used Participant B and his staff team for this example of this process. Beginning with participant B, I consider each question in turn, summarising his responses to this question across the three SSIs and highlighting any changes that occurred over time. I then summarise my thoughts about the responses.

Participant B

Question 1: <u>In this last week, since last Tuesday, have you self-harmed, in other words, hurt yourself on purpose?</u>

Derek's responses included: Confirming that he had and giving vivid, visceral descriptions of what he had done, describing incidents in rich and dramatic detail; denying any self-harming but in a rather defensive way; offering a more balanced view of his self-harming, describing a decrease in frequency and with less dramatic detail.

Researcher's thoughts: In the first SSI at the start of this research study, Derek would discuss his self-harm in graphic detail. Here is an example of this from Derek's first SSI:

'And it's all running down here. Couldn't stop it. All bleeding. Couldn't stop it.'

I was aware that Derek possibly needed to shock me or make me feel overwhelmed, perhaps to see if I could survive his self-harming. I felt that he wanted me to really see and understand his pain both physical and emotional and also to offer him sympathy. In the second SSI Derek was much more defended against thinking about his self-harm:

'Haven't done it at all. I've stopped doing that now.'

On this occasion, Derek was very resistant to thinking about his self-harming at all. It became clear from some of the later questions in the SSI that Derek was aware of negative feelings and responses from the staff team to his self-harming and I wondered if Derek was anxious about how I might respond if he told me that he was continuing to self-harm. By the third and final SSI, I felt that Derek had a much calmer and more open approach to discussing his self-harm. He described a reduction in his self-harming and also greater insight into what caused him to self-harm when he did. There was a notable absence of visceral descriptions and drama. His descriptions were honest, factual and contained:

'I hurt my arm last week. I was angry.'

Question 2: <u>How often have you self-harmed or hurt yourself on purpose?</u>

Derek's responses included: Derek told me that he had self-harmed a few times, not at all and just once over the week leading up to when the three SSIs were administered.

Researcher's thoughts: There was a marked difference in Derek's response to this question over the time of the study. By the end of the study there had been a significant decrease in Derek's self-harming with both Derek and the staff team describing this as hardly significant:

'But I don't really do it (self-harm) so much now. I talk to the staff more.'

Question 3: <u>How did you hurt yourself? Can you tell me what you did?</u>

Derek's responses included: A description of cutting himself with broken glass from a picture frame that he had smashed, banging his arm against a chair, punching objects and rubbing his legs with a towel to cause friction burns.

Researcher's thoughts: Derek's methods of self-harming changed over the course of this research study. At the start of our work, Derek's self harming was more frequent

and frequently involved cutting himself, either with glass from something he had smashed or by banging his arms or legs against something so hard that they would bleed. As his self-harming began to reduce his methods for hurting himself became less dramatic and also less dangerous. During the early phase of our work in between the first and second SSI Derek broke his arm by bashing it against a door frame. This gave him quite a shock and he seemed frightened by what he had done and the strength of his feelings. It was after this, in the second SSI that Derek denied any self-harming and said he had completely stopped doing it. I think this was, in part, a response to the fright he had given himself by breaking his arm. By the third SSI, Derek's self-harming was both less frequent and less dangerous. His injuries were mainly friction burns on his legs from rubbing himself with a towel and bruises, as opposed to broken bones and open wounds. He had also found a way to acknowledge the times he did self-harm in much less graphic and sensationalist terms.

D: *'Hurt my arm last week…Done it on the chair.*
Int: *I see you've got a bruise there.'*

Question 4: <u>Do you know why you hurt yourself? It's OK if you don't know why you did it.</u>

Derek's responses included: He missed his mum and dad, he was angry, he was stopped (by staff) from doing what he wanted and was annoyed by the other people he lives with.

Researcher's thoughts: Much of Derek's self-harm seemed to stem from anger towards the people he shared a house with. If Derek was thwarted from doing something he wanted, his response was often to self-harm. As well as expressing his anger, it also ensured that the person who had stopped him from doing what he wanted or had made him angry felt guilty and responsible for Derek's self-harm.

'He was upset about my hand. He started crying.'

Derek would describe overwhelming and sudden feelings of anger that often acted as a prelude to him self-harming:

[Of anger] *'Just came over me, it did. Like that.'*

Although Derek could articulate that he was angry or missed his Mum or Dad, it was difficult for him to think about what had actually led him to self-harm in a given moment. He could describe the bleeding and the drama of the self-harming and say in a general way that he was angry or upset but thinking about what might have gone wrong between him and the person that had upset him remained unavailable for Derek to think about for quite some time. One of the significant changes over time was the way in which Derek started to see the staff as helpers and sources of support, rather than opponents. By the third SSI Derek was much more insightful about the things that made him angry and the way misunderstandings occurred between him and other people. He also more readily approached the staff to talk through things that were upsetting him rather than self-harming:

'...sometimes,still get angry...yeah, but I talk to the staff I do.'

'... tell someone when I'm angry. It's different now.'

Question 5: <u>Did you feel better after you had hurt yourself?</u>

Derek's responses included: Derek described feeling worse after self-harming but on another occasion described feeling better after he had self-harmed.

Researcher's thoughts: My sense was that whether or not Derek felt worse after self-harming depending on what had happened just before it and the way in which he had injured himself. The times when Derek described feeling worse after self-harming were when he had felt suddenly and inexplicably angry and caused himself a significant injury. When he broke his arm and cut himself with glass from a broken picture frame,

he had clearly shocked himself. The physical injuries were sufficiently significant that he felt anxious and uncomfortable:

'I couldn't move this arm, this hand and I was shaking. A bit nervous.'

'That frightened me, yeah. That did.'

When Derek described feeling better after self-harming he had been engaged in an argument with someone he lives with. Derek and the other resident have a long history of conflict and whilst this has been thought about both with Derek in music therapy and more widely within the MDT and Derek's staff team, it would seem that there are some fundamental differences in personality and lifestyle that really do make Derek and the other resident incompatible as fellow tenants. I will return to this in the concluding part of this chapter. In this later incident of self-harm, Derek was much more able to describe what had happened, both in the way the other resident had made him angry but also acknowledging in a small way, how he contributed to the argument:

'I called him names.'

I noticed that when Derek's anger built more slowly and he had time to think about what was happening, his self-harming was less dangerous in terms of the physical injury. He seemed to choose methods of self-harming that took more time such as rubbing his legs with a towel which takes a while to cause friction burns, or repeatedly banging his arm or leg until it bruised. Whilst there may be many different reasons why somebody might self-harm, research studies have shown that it may offer temporary respite from emotional distress through the release of endorphins, opiates, oxytocin. These chemical releases are a physiological response to injury (Haines et al., 1995). I wondered, in Derek's case, if when he injured himself to a more dangerous level, e.g. breaking bones or causing significant bleeding, the chemical release was outweighed by Derek's sense of panic about what he had done. He often spoke of feeling dizzy and of shaking. He was also very aware of the physical pain of his injury. This might have prompted him to answer that he felt worse after self-harming. When he had a longer

period of emotional arousal, in other words, was engaged in an escalating argument rather than a sudden loss of control which took over him with little warning or build-up, both his feelings and his self-harming unfolded more slowly. Perhaps this allowed him to make use of the chemical release of endorphins, opiates and oxytocin so that he experienced self-harming as a welcome release and could therefore say that it made him feel better.

Question 6: <u>What did the staff do when you hurt yourself?</u>

Derek's responses included: Derek described the way staff helped attend to his wounds or took him to a minor injuries unit or the GP. He also spoke of talking to the staff about why he had self-harmed and feeling that they had listened to him.

Researcher's thoughts: Derek was able to clearly articulate the ways in which the staff helped him in practical ways. It was harder for him to think about their emotional reaction to his self-harming although he could describe to me the practical measures the staff took to manage his injuries:

'She put one of those bandage things on. Then she tied it up and went to the surgery and then to the hospital. Went to the surgery first and then C [member of staff] *had to take me to the hospital.'*

During music therapy sessions we started to explore how Derek thought the staff might feel when he self-harmed. He was very quick to tell me that they didn't like it and that it made them upset. I wondered whether his sense of the staff's upset conferred upon Derek a sense that he mattered to them.

Question 7: <u>Were the staff helpful?</u>

Derek's responses: During the SSIs Derek consistently said the staff were helpful and would offer examples of this. The nature of the help he perceived the staff as giving

changed throughout the study. Initially he focused on the practical help staff gave him when he had self-harmed:

'She did help me…wiped the blood off and pressed it to stop it.'

As we progressed through the work, Derek's focus shifted to the emotional support that the staff provided him with.

'Sometimes they help me when I can't do it myself…or when I get angry… They listen to me.'

The eighth and final question which was asked in the second and third SSIs only (owing to the intervention of music therapy having not started at the point of the first SSI) was:

Question 8: <u>Do you think music therapy has been helpful? If, so, can you tell me how it has helped you?</u>

Derek's responses included: Derek described clearly the ways in which music therapy had helped him. He spoke of it helping him to relax, offering him someone to talk to about feelings, a place to think about his parents, somewhere to think about his self-harming and a place to play music.

Researcher's thoughts: After some initial uncertainty in engaging with music therapy, Derek became extremely committed to the sessions. Breaks to this work were minimal and planned for, but he clearly found them difficult. He needed to tell me how much he had missed me and I sensed his anxiety about abandonment and being forgotten about during breaks:

'I missed you last week, I did.'

'It helps me to come here. I can come and talk to you. Playing music makes me relax and I can talk about me Mum and Dad.'

Participant B's staff team

The same process happened for Participant B's staff team.

Question 1: <u>Can you describe the ways in which Derek self-harms?</u>

Responses from members of the staff team included: refusing to take medication; kicking furniture; banging his hand or head against hard surfaces; punching things; tearing his clothes; giving himself friction burns; interfering with wound healing; breaking objects and then using the broken pieces to injure himself.

Researcher's thoughts: During the first SSI, staff spent considerable time describing Derek's episodes of self-harm to me in dramatic and graphic detail. Here are some examples of their responses:

'Kicking things…injure his foot. He'd kick things in order to hurt himself. His bed… he'll walk into. You'll see him bang against table legs or doors.

'Or he'll bang his hand on a cupboard door; he's hit his forehead on the corner of a door…Gives himself friction burns with a towel.'

'He's even broken his wrist by banging it against a wall when it was starting to heal. When the cast is coming off, he'll re-break it.'

'And even I, when I see it, it makes me cringe having a plug whacked into your forehead and stuff…'

The speed of delivery was very fast and staff frequently interrupted each other to tell me about an increasingly serious incident. There was an element of competitiveness about who had witnessed what, as if responding to a more serious incident of Derek's self-harm made that staff member feel more important:

'Even after he'd had it bandaged…erm…and the bandage came off, he…because I had to change it…and he was like: "You can't do it, a nurse has to do it" and S [staff member] *was like: "Well, she used to be a first-aider, so she's more than capable of doing it. She spent years in the Red Cross and St John's Ambulance…"And I was like: "Yeah, I'm more than capable of cutting it off and actually it's not too bad, we'll just let it breathe." '*

SGF's thoughts: The SGF felt that the staff team discussed Derek's self-harming in quite a fearful way in the early groups. Staff expressed concern that if they said 'no' to Derek, they would cause an episode of self-harm and would therefore be responsible for any ensuing injuries. The staff team were very self-critical and felt that they were being judged by managers according to Derek's behaviours. The staff team also described Derek's self-harming in dramatic and visceral detail but found it much more difficult to think about what might have led Derek to self-harm and how he might have been feeling. The SGF was struck by the dramatic descriptions and wondered if in some unconscious way, the staff found Derek's self-harming to be an exciting alternative to the otherwise boring, daily grind of the household. It seemed that staff felt that by being the person to treat Derek's injury it conferred on them a sense of importance and value in their job role.

Question 2: <u>During the last 4 weeks how many times has Derek self-harmed?</u>

Responses from members of the staff team included: 7 or 8 incidences; a staff member checking against the behavioural forms that staff keep as a matter of course; a description of the glass incident; a description of the bread incident; a description of the smoke-detector incident; a description of Derek self-harming because of not being allowed to have sweets; descriptions of three or four incidences where staff suspected Derek had self-harmed in his bedroom and appeared with injuries. In the final SSI staff reported that self-harm was far less of an issue for Derek.

Researcher's thoughts: There was some disagreement among the staff about what constituted an incident of self-harm and what was considered to be Derek pushing the

boundaries. We agreed that an episode of self-harm had occurred when Derek had a visible injury. It was difficult to clarify the exact number of self-harming incidences because staff suspected that some of these had occurred in secret, hence the estimate of 7 or 8 incidences. By the final SSI at the end of the study staff reported no incidences of self-harm over the past 4 weeks:

'Do you remember that time when…he was having a set-to with (another resident) and he went to bash his arm, but then he thought about it, hesitated and he didn't do it… Yeah, that is different now.'

In the final SSI and in response to a question about the frequency of Derek's self-harming and whether or not it had lessened, the team leader gave the following response:

'Yeah…I don't really think the self-harming is much of an issue now.'

Question 3: <u>Do you always understand the reasons why Derek self-harms?</u>

Responses from members of the staff team included: he does it to show-off; he does it when there has been a change to his routine; to manipulate the staff; to bring about an outcome that he wants; as an avoidance strategy; if he feels unwell or is in pain; if he feels 'badgered' and wants some peace and quiet; if he is angry; if he doesn't want to take his medication.

Researcher's thoughts: When I first asked this question the staff team were rather negative in their responses, describing Derek as showing off and being manipulative. There was a lack of warmth from some of the staff and even some aggression expressed towards him. Here are some examples from the transcript:

'I thought that seems a really nice day we've had and so I gave him his cigarette before I gave him his medicines [a change to the usual routine that Derek was used to], *and because there was somebody else here* [a visitor], *I think he used that as…I dunno…a*

showing-off point.' [Having been given his cigarette, Derek then refused to take his medication. Staff member D, who had changed the routine had to phone team leader S to come and assist him.]

Team leader S: *'I came in. I came in and got him to take his medication. Fresh face, different thing.'*

Staff member D: *'And I thought: "Right Derek, you won't get me like that again." '*

I was struck by the staff's ambivalence towards Derek and how angry staff member D appeared to be by the thought that Derek had manipulated him in some way. Another staff member also expressed ambivalence towards Derek, as this example from the transcript reveals:

'I must sound really wicked, but when he says: "Ouch my foot hurts" I just make a joke of it.'

Shortly after this statement, a quieter, newer member of the staff group offered a very different, more compassionate response that allowed for the possibility that rather than being manipulative, Derek's self-harm might be an expression of something more complicated and rooted in trauma:

'…there may be underlying issues, you know, traumas that go way back , that kind of… erm…trigger off these actions, like the trying to get the puzzle pieces in, that obviously they don't fit, they're not the matching pieces, and he bangs his fist, it might be a repetitive action that he's used to from his home life as a child or something, so there might be a thread there that has something to do with all of this.'

This seemed to be a much more forgiving view of Derek, which then seemed to alert other members of the staff team towards a more compassionate view of the reasons for Derek's self-harming:

'…if he has medical problems, so if he's got an ear infection or stuff, he doesn't necessarily say, so he's less tolerant of other things…I don't always think Derek always feels pain… It's like there's a niggle, like if you've got… there's some like muscle pain or something, you know it's there, it doesn't really bother you that much, but you know it's there and it's tiring and it drains you, and so then actually, you're like, not 100%, so if somebody does something and then actually you'll…where you'd normally tolerate that you don't tolerate it. That's definitely a thing for Derek and we always think medical with him.'

Here, the staff show that they could use their own experiences of being in pain to empathise with Derek.

SGF's thoughts: The SGF felt that the staff team talked about Derek using self-harm as a way to avoid demands. The staff team also wondered whether self-harm offered Derek a legitimate means of gaining physical contact and provided him with some sensory experience that would otherwise be unavailable to him. In other words, when he self-harmed staff physically touched him as they attended to his wounds. Given the staff's adherence to professional and appropriate physical boundaries with the service-users that they support, Derek was unlikely to receive any expressions of physical warmth such as a hug or physical comfort. Self-harm therefore afforded him a legitimate means of receiving some form of physical connection.

Question 4: <u>What is it like for you when Derek self-harms?</u>

Responses from members of the staff team included: a sense of blaming themselves; feeling angry with Derek; an acknowledgement of mistakes the staff might make that might precipitate an episode of self-harm for Derek; trying to understand why Derek has self-harmed; feeling warmth and concern for Derek; feeling frustrated with Derek; feeling angry with themselves for not knowing how to prevent Derek from self-harming; feeling anxious about trying to prevent an incident of self-harm; blaming each other for not adhering to agreed guidelines which might lead to Derek self-harming.

Researcher's thoughts: When members of the staff team first responded to this question, their responses suggested that they felt a significant burden of responsibility for Derek's self-harm. Staff spoke of blaming themselves and each other, feeling frustrated that mistakes may have been made that may have caused Derek to self-harm.

'I do get annoyed with myself thinking that if I'd done that a bit more differently, or that staff member shouldn't of done that… But I've been doing this for so many years and to make a simple mistake like that and I feel annoyed with myself, you know what I mean?'

'I should have known that…you start kicking yourself.'

They also needed to express how hard they tried to prevent situations that might have precipitated an incident of self-harm; it seemed important for the staff to feel that the efforts they went to were fully understood:

'…but the effort that goes into it from our point of view is obviously a lot higher, a lot greater.'

'…it's about how we try to prevent things…we try and analyse it…we definitely try and solve what it is that could be bothering him.'

'I constantly run through my head about other ways we can help him.'

Staff were also able to express their disappointment for Derek when he self-harmed, mainly when the result of this meant seeking medical treatment rather than doing whatever else had been planned for the day:

'But you also feel disappointed for Derek, because actually when he's hurt himself you think: "Argh, but you could of gone out" or "Now you can't do your bike riding or you can't do this." '

Staff clearly experienced high levels of anxiety in trying to prevent a situation in which Derek might self-harm and at the beginning of this study this was a significant preoccupation for the staff team. This next extract gives an example of how panicked the staff could feel. The context is that Derek had asked if he could have a bath:

' "Can I have a bath?" and instantly you get them feelings inside like: "Right. Ok. God, right, I'll get your bubble bath," otherwise you know that can just lead to him pouring the whole thing and then he goes: "I ain't got no more of that" and than can all lead… so you can't think of all of the things that could possibly happen…so it's like a military, precise operation that you have to do. So in your head you have to, like, risk assess it, plan it, and you think, because it's actually …I can't…I don't want it to go wrong.'

'The other day I was stressing because I couldn't find the ear plugs and I was thinking: "Argh, I feel like I've failed already because the ear plugs aren't where I thought they were going to be,", so instantly you feel heightened and you think: "Right, I'm on a time limit now." '

The tone of the responses then started to change with staff blaming each other. Splits within the staff team were starting to emerge:

'But you gave him (Derek) his mints earlier because you thought he was getting a bit negative…but by doing this… that changes kilter, you've kind of…you've actually broken the guidelines as such for us all to follow which can then have an effect on his self-harming.'

'You get yourself into a nice little routine with Derek and we've got a good relationship going. And then you have, like a few days off and someone else takes over, and that's it, that routine's all broken. You have to start again.'

The blaming was quite subtle and within the context of the SSI it was politely acknowledged. I was interested in how these splits within the staff team were being played out in the monthly staff groups.

SGF's thoughts: A sense of competitiveness quickly emerged in the staff groups, with staff seeming to compete for who could best understand Derek and prevent or manage his self-harming with staff sometimes blaming each other outright for particular incidences of self-harm:

'He hit his arm in the door cupboard. That was your fault.'

There was a clear sense of a staff hierarchy and a competitive sense that all the staff wanted to be seen to work equally well with Derek:

Staff member E: *'With me, he'll come and ask.'*
Staff member T: '*He does come and ask me as well.'*

The team leader was often acknowledged as the person that would come in when other staff were unable to manage a situation. This caused great envy and rivalry between the staff which was able to be explored within the safe parameters of the monthly groups.

'He accepts certain things from me more than others because he knows that I'm at a different level.'

The monthly staff groups provided a supportive arena within which some of these splits could be thought about. This allowed the staff to directly encounter the effects of these divisions and to find new ways of working together more cohesively. These are some quotes from the final SSI at the end of the study:

'It feels like we are a proper team now and we respect each other, and the consequences of that obviously affects everyone and you can see how ultimately that helps D.'

'I think it's been part of this project and the groups that it's enabled us to step back and look at it differently. I look at things completely differently to how I did before these meetings.'

Question 5: Do you have an agreed way of responding when Derek self-harms?

Responses from members of the group included: 'We sort of do'; an uncertainty about how much agreement there is about how staff respond to an incident of self-harming; an acknowledgement of panic and not always being able to think about what it might be best to say or do; a sense that when Derek self-harms it could be 'horrific' and the situation is heightened; some staff members acknowledge feelings of frustration towards Derek which impacts upon how they might respond to his self-harming; other members of staff are less prone to panicking and can make a calmer response; one member of staff felt manipulated by Derek's self-harm and tended to walk away and ignore it.

Researcher's thoughts: When this question was asked of the staff during the first SSI the language used was heightened and anxious by some members of staff:

'It could be horrific. So…like…if it's like the picture frame thing and there's blood pouring out of someone's hands and you're already heightened and in your head…'

'And even the response of other people because they are really affected by it. They get really upset at seeing it, and even when I, when I see it, it makes me cringe having a plug whacked into your forehead and stuff'.

'Inside you're screaming and crying but you can't show him.'

For other members of staff, how they understood Derek's self-harming affected how they responded to it. For staff member Peter, who felt that Derek's self-harming was a form of attention seeking, the response was to walk away:

'Yeah, you just have to walk away…otherwise he'll carry on doing it over and over again. Once he's got your attention or something like that, he'll carry on doing it.'

Of course, when Derek self-harmed, he would present his injury to whichever member of staff was on shift at the time. It was notable at the start of this study that the staff team had very different ways of both understanding and responding to his self-harm. Peter's reaction represented one end of a spectrum of ways in which the staff understood and responded to Derek's self-harming. Other members of staff spoke of being angry with themselves but with the occasional glimpse into their annoyance with Derek for self-harming:

'I do get annoyed with myself thinking that if I'd done that a bit more differently or staff member shouldn't of done that…lots of different things, but…er…in the beginning it was quite rough, and …um… he was quite annoying and sometimes I'd get quite angry with myself…'

Other staff members have a physical response when they see Derek injure himself:

'I cringe when I see him do it.'

One of the significant changes that took place during this study was a greater sense of staff cohesion, a sense of them working and thinking together. For Derek this meant a more predictable, coherent response. In the words of one staff member:

'When staff ring me, you can hear it and it's really different: "This has happened. It's OK, everyone is fine, dealt with it, this has been done, that has been done"…And then the next day, we just look at it, see if anything needs doing and then we carry on… Whereas before, everyone was worrying that this was going to happen, or it looks bad… or "Should I have done this?" And we try to accept now, reflect on it: "Yeah, I suppose I could have done that" but actually you can't control everything… Before the music therapy and staff groups, we felt we had to control everything, and had to avoid it (Derek self-harming) at all costs and if he did it, it was our faults, we kind of caused it.'

SGF's thoughts: In the groups the staff were able to think about how they responded both individually and as a staff team to any incidents of self-harm. It became clear that

how staff responded to Derek when he had self-harmed correlated to how they felt about the fact that he had deliberately hurt himself. For staff member Peter, who had worked with Derek for many years, there was little expectation or prospect of change and in the second SSI he expressed the view that nothing was changing:

'I think he's still the same actually. Derek's just Derek. He's going to have his up and down days, and the therapy, I don't think it's achieving anything really.'

When Peter was asked about how he responded to Derek, as described above, he said he walks away believing that if he stayed with Derek it would reinforce and maintain his self-harming behaviour. Six months later, Peter's view had begun to change:

''Cause I've worked with him for the longest, he was, to be honest, ten times more difficult than this. There was always loads of forms and paperwork to be filled in at the end of the day. He has got a lot better, he is a different kind of person. But his behaviour is a bit difficult…I think he's always been that way.'

There is a paradox here between the idea that nothing can change, that Derek will 'always be that way' and an acknowledgement that things have changed rather significantly. Peter states that Derek used to be much more difficult and that he is now 'a different kind of person'. The SGF noticed the ways in which the staff team could quickly become fixed in a negative view of Derek, often ascribing the worst motives to Derek's behaviour and self-harming. In the first six months of the group she noticed that staff would describe Derek as attention-seeking and manipulative and would describe him as behaving differently with certain members of staff:

'Sometimes with new staff, he'll try it on with them.'
'If he knows he's not gonna get a response, he tends not to do it.'

The SGF and I were struck by the conscious and deliberate intention that the staff team ascribed to what they perceived as Derek's manipulative behaviour. It was difficult for them to hold in mind Derek's learning disability and the impact of this on his capacity

to be deliberately manipulative. It seemed easier for the staff team to dismiss Derek's learning disability and allow themselves to believe that his actions were within his conscious control. This position allowed the staff to be justifiably angry with him because they perceived his actions as intentional. To acknowledge his learning disability as an influence on his behaviour might have meant a more uncomfortable confrontation with their own angry feelings towards him.

Question 6: <u>How do you see the music therapy sessions? Do you think they are making any difference for Derek?</u>

In the first SSI, because the music therapy sessions had not yet started I asked the group about their hopes and expectations of this intervention:

Responses from members of the group included (from the first SSI thinking about hopes and expectations of music therapy for Derek): belief and hope in the possibility of change; the staff's sense that Derek experiences a lot of emotions that they do not always understand; he will enjoy the attention; he won't stick at it and one member of staff who felt it wouldn't make any difference. (From the second and third SSIs): positive acknowledgement of the benefits to Derek of attending music therapy; a sense that he is calmer; he talks more to the staff about his feelings; music therapy has given Derek a space to express himself and he is less explosive now.

SGF's thoughts: During the first SSI some staff members expressed the expectation that Derek would benefit from having music therapy:

'I think it will really help him to have a space away from all of us to talk about things, because, you know…he's like…well he gets so that he doesn't always talk to us. We almost have to get stuff out of him and I think there's so much in there and we don't always know how he's feeling.'

I was struck by the staff's curiosity about how Derek might be feeling and their acknowledgement that a neutral space, away from home, might afford him a space to

process some of his emotions. Another staff member, Peter, was less optimistic about the potential benefits of music therapy:

'I don't think so, that's my personal view. I think Derek will enjoy the music therapy but I'm not sure it'll change anything. Derek's just Derek, that's how he is.'

I reflected back to the staff that perhaps it was difficult to imagine that things might change.

By the time of the second SSI, Derek had received six months of music therapy. Whilst Peter remained unconvinced that music therapy was helping, other members of the staff team had a different view:

'*I think that he is getting something from it.'*

This staff member, Des, went on to explain that where Derek used to explode and self-harm he is more likely to get angry which would cause what staff called a 'behaviour' (verbal aggression, walking off) rather than an incident of self-harm. Another staff member, Tina, gave a recent example of Derek wanting to eat four ice-creams. A staff member challenged Derek and asked him to put two back in the freezer. Derek became angry and threw the ice-creams across the room. Tina described Derek as sinking to the floor as if about to hit his arm on the floor but stopping himself and pulling down some curtains instead. Given that a few weeks earlier when Derek had been told he could not have something he wanted, he had broken his arm, staff were able to consider this as a positive development. They were also able to reflect on how things had changed over six months:

'When this work first started, when Derek first started seeing you (for music therapy), the staff were, quite honestly, in despair with how his behaviour was having an effect… When he first came to you, he had an injury…and then he did a bit of rubbing with the towels and stuff and that kind of thing, and he had been banging his elbows…we had quite a bad patch of self-injuring just before he started with you. I have to say there

hasn't been in the last few months any actual physically self-injuring himself. It has been minimal.'

'And I think the music therapy has had a big effect on Derek. He talks more to us now and things don't build up like they used to.'

By the final SSI at the end of the study there was much more agreement among the staff about the impact of music therapy for Derek:

'I think it's been really, really beneficial. Before this, Derek used to keep everything really bottled up…kind of…he would not say anything then "Argh" there would be an explosion and he would go from seeming OK to self-harming. Now he talks more, and I think that's because he's had the space to express himself with you. It's definitely made a big difference.'

'You can see the benefit to him afterwards and it's like he can talk about stuff with you, that he doesn't talk about with us, or that perhaps gets a different response from you. He is able to play it out through music and stuff… "I'm playing music and this is how it makes me feel, this is about me," and that's what happens at music therapy.'

Question 7: <u>How have you found the staff groups?</u>

Responses from members of the group included: staff reported finding the groups helpful as a place to vent; giving them a sense that when Derek self-harms it is not their fault; a place where they don't feel scrutinised and blamed; a place in which to explore new ways of understanding Derek; somewhere where staff can step back and gain a different perspective and somewhere to think about the strategies staff use to manage Derek's self-harm.

Researcher's thoughts: The staff team have been consistently positive about their experience of the monthly staff groups. Both my research assistant and I have been struck by the commitment the staff have made to attending the groups with some

members coming to the groups on their day off. The staff shared openly their experiences of working with Derek and, with support, have been able to acknowledge the conflicts and difficulties arising within themselves as a staff team. In particular they have been able to express a greater sense of acceptance if Derek does self-harm rather than needing to blame themselves or each other:

'Before, (the groups), everyone was worrying that this was going to happen, or it looks bad, or "should I have done this?" And we try to accept now, reflect on it. "Yeah, I s'pose I could have done that" but actually you can't control everything, which is what we felt we had to do. Before the music therapy and the staff groups, we felt we had to control everything and had to avoid the self-harming at all costs and if we did, it was our faults, we kind of caused it.'

Another staff member spoke of life in the house as feeling much calmer as a result of having the monthly staff group space to talk about the anxieties she felt when Derek self-harmed:

'Now it's calmer. We just deal with it, put it away and go on being there.'

At the end of the final SSI the staff spoke of how meaningful it was for them to have been invited to participate in a research project. It gave them a sense of value and confirmed an importance to both what they do, as well as a respect for the knowledge and experience they have in supporting someone with a learning disability who self-harms. Here, two members of the staff team are thinking about telling their managers that they have taken part in this study and made a valuable contribution to research about people with learning disabilities that self-harm:

Staff member S: *'I feel like…putting it in a letter and then send it to (her manager) and (her senior manager).'*
Staff member T: *'Seriously, send it to them.'*
S: *'The whole thing about helping with research, that's really good.'*

T: *'It's not something we've been asked to do or been involved in before and I've enjoyed it.'*

The team also spoke of feeling that they had gained some knowledge. There is a sense of them feeling empowered by having new ways of understanding Derek's self-harming:

'And you can understand it [Derek's self-harming] *more and take it on board and actually feel like you've got a bit of that knowledge as well.'*

SGF's thoughts: In the second six months of the group, there was a perceived shift from the anxieties expressed in the earlier groups to the expression of more hostile and ambivalent feelings towards both Derek and each other. A professional from the MDT had suggested (in front of Derek) that he should move into a single person accommodation and although this was initially met with anger from the staff team, they quickly became very hopeful about this as a solution to both Derek's self-harming and the difficult dynamics between the three men who lived at Juniper Close. Derek quickly seized upon this idea and became fixated on the idea that he had been told this would happen. The staff team's initial resistance and anger towards this idea came from a concern that Derek might be let down (if a house move did not happen for him) and that they would be left to manage the consequences. They used the group to vent their anger with our team for suggesting this to Derek. However they quickly became interested in the possibilities and potential benefits of such a move and they themselves became quite fixed on this idea. It helped to create a fantasy that the dynamics in the house would improve if Derek moved out. For a time, he became a scapegoat for all that felt difficult and unmanageable within the house. Within music therapy, Derek was able to think about his ambivalence about moving; it became clear that the staff represented an important model of family life for him and his relationships with the other men he lived with, although sometimes turbulent, were rather affectionate also. We were able to think about how Derek might talk to the staff about his mixed feelings; the staff then had the group to think about their responses to Derek's feelings about moving. Once staff felt that their anger with our team had been heard and validated they were able to

start to think about things from Derek's perspective. In particular, staff were interested in Derek's lack of family and the ways in which their role mirrors that of a family, whilst also being very distinct and different from it. The following excerpt from the staff group shows how difficult the staff found it that Derek has no family of his own. It also demonstrates that the staff could be very moved by Derek and could feel genuine empathy for his situation:

Staff member S: *'I think he's really desperate. He often talks about his brother and has done for years and years… he would say: "My brother doesn't come to see me" and he would miss that….he will ask everyone how their mum is, or "How is your wife/ husband," but you can't say them back to him.'*
Researcher: *'And that's painful for you too isn't it?'*
S: *'It really is.'*

On another occasion a staff member was describing trying to eke out Derek's bedtime so he wouldn't go to bed too early and then wake during the night. This extract shows the extent to which staff had become very fond of Derek and valued him:

Staff member T: *'One day he (Derek) was really tired and wanted to go to bed early: it was about 6:20. I managed to eke it out because he had not had his nuts to eat for his supper before going to bed…and he came up to me a couple of times and I said: "I haven't forgotten"…I came downstairs to find him so he didn't have to come and ask me again and he said: "I've done all the washing up for you" and he'd done all the washing up without being asked…I could have cried.'*
Researcher: *'So did he see that reaction in you?'*
T: *'Oh, we had a hug. That's what keeps us going, those split seconds…'*

Participant B

First semi-structured interview: 5th January 2016

Int: *We're going to spend about 20 minutes talking about the times when you hurt yourself when you feel really unhappy. I've got a few questions and there are no right or wrong answers.*

D: No, there's not, no...

Int: *None at all. Is that alright?*

D: Yeah, that's alright. I don't mind.

Int: OK. In this last week, have you hurt yourself on purpose?

D: Yeah (stammers...) You know my picture frame?

Int: Tell me about the picture frame.

D: It's in the lounge.

Int: Mmm.

D: And something went straight in that glass and that's all running down with blood (mimes punching the frame)

Int: You did that? You punched the picture frame?

D: Yeah, I hit the glass... well...

Int: (Quietly) OK... It's a huge bandage. It looks like you hurt yourself quite badly…

D: Yeah. Like that I did (shows a punching action with his fist)

Int: And did the glass break?

D: Yeah, and the blood went all down my fingers.

Int: I see. The blood ran down your fingers...

D: Yeah, and I went to hospital.

Int: Did you?

D: Yeah...

Int: Mmm…

D: I can't do things, I can't use this one. Not yet. Then I can't put my watch on. Not yet.

Int: OK. So does that mean you need other people to help you with things?

D: Yeah. See, I can't use it yet.

Int: I am wondering if you were feeling upset about something to have smashed the picture frame and hurt yourself so badly.

D: Yeah.

Int: Can you remember what you were feeling so upset about?

D: pauses: I miss my mum, that's what it is.

Int: You miss your mum...

D: And my dad.

Long pause

D: And this time, I can't do my laces up. I can't do them with this hand.

Int: Mmm.

D: I was in hospital for 3 hours.

Int: Were you?

D: 5 o'clock. Didn't finish at 6....when we got back. Got back at half past 8.

Int: So it was getting late when you arrived home. When did this happen?

D: Over the weekend.

Int: Over the weekend, so just a few days ago.

D: A few days. If that goes all red, I go back again.

Int: Back to the hospital? And would you like to go back to the hospital?

D: No, I wouldn't…no. I miss my mum and dad I do.

Int: And I know they're not here anymore are they?

D: They died a few years ago now, yeah. Yeah... before Christmas I thought about her. (pause) That was a long time ago weren't it?

Int: Well... (pauses to think and go on...)

D: Sometimes it aches sometimes on top of these... Me knuckles are a bit sore.

Int: Even things that happen a long time ago can still be very painful and make us feel very sad. I wonder if missing mum and dad feels a bit like an ache too.

D: Yeah, that will.

Int: And losing important people like mum and dad can make us feel sad for a very long time.

D: Yeah...

Int: Can you tell me a little bit more about how you felt when you punched the glass?

D: Yeah I was angry I was.

Int: OK so as well as being sad about missing mum and dad you were also feeling angry.

D: Yeah, I was very cross.

Int: What made you very cross?

D: I dunno. Just came over me like that.

Int: Came over you like that. Very suddenly.

D: Yeah.

Int: Were you upset with anyone?

D: Yeah it was E. (staff member). She made me do it.

Int: E?

D: Yeah, one of the staff at the.... I live in (names village)

Int: Mmm

D: Then she said:"You mustn't stand on the settee." Yeah: "You mustn't stand on the settees." That's it, she told me to get off. I went straight like that (mimes breaking the glass frame).

Int: OK. So can I make sure I've understood exactly what happened. So you were standing on the settee.

D: Yeah, I was.

Int: Why were you standing on the settee?

D: I was putting a battery in the smoke alarm.

Int: OK.

D: Yeah.

Int: So had Emma asked you to do that?

D: No. They don't let me do it.

Int: OK. So you felt that the battery needed changing in the smoke alarm.

D: Yeah.

Int: I see.

D: Mustn't touch electrical wires, mustn't touch them. You'll get an electric shock.

Int: Is that what the staff have told you, that you mustn't touch electrical wires.

D: Yeah that's right.

Int: And you thought: "I want to do this anyway" and you stood on the sofa and then Emma asked you to get off the sofa, is that what happened?

D: Yeah. Told me to get off.

Int: And that made you angry because you wanted to change the battery.

D: Yeah.

Int: OK. And because you weren't allowed to do what you wanted to do, you felt very angry and that's when you punched the frame.

D: Yeah.

Int: OK

D: You're pleased to see me back?

Int: It's good to see you...
D: It's nice to see me back here. You came to my house didn't you?

Int: It is. I did… (pause) I know that this is difficult to talk about… Is it OK if I ask you a couple more questions?

D: Yeah that's OK.

Int: I am wondering how you felt after you hurt your hand. Did you feel better afterwards, or worse?

D: Worse.

Int: You felt worse.

D: Yeah.

Int: Can you tell me how you felt?

D: I couldn't move this arm, this hand and I was shaking. A bit nervous. And shocked.

Int: Shocked. I wonder if you were shocked by what you had done to yourself?

D: Yeah I was. Can't use this hand in the bath. Not yet.

Int: So you can't get it wet.

D: I've got to keep it out.

Int: I see. You've told me that it was painful, you couldn't move your hand and you were shaking. Have I understood that right?

D: Yeah. It was painful, that was. Yeah.

Participant B's staff group

First semi-structured interview with staff group: 21st January 2016

R: There's a bit of a preamble first, just because I'll read this to everyone. So, these questions, we'll do them today, I'll come back and see you in 6 months time and then I'll see you a year from today at the end of the study. In between times you'll see [SGF] for your monthly groups and she'll get in touch with you separately about this. So during the study I want to measure any changes in terms of how the service-user that you support self-harms. I also want to measure any changes in terms of how you understand self-harm, what you think it might mean for D. and how you respond to it.

I'm going to ask you some questions which will take the form of a semi-structured interview which we will have around the table. [Participant information sheet is read out.]

Int: Can you describe to me the ways in which D self-harms?

T: Medication's a good one. He will put the inhaler up his nose if he's not in the mood for taking his meds. He'll put it up his nose.

Int: What's the inhaler for?

T: He's got asthma.

E: COPD, that's what he's got (Chronic Obstructive Pulmonary Disease)

P: (Named drugs) they sort out his lungs and settle his breathing.

Int: So he has to inhale this?

T: Yes. Through his mouth

Int: Through his mouth? (clarifies)

T: But he tries to get attention

S: He sees it as a demand. So it's even like his tablets and he'll say :"Bloody hell, not those again,I've been taking them for 3 years." So, and then, and obviously, we're like, we need him to take his inhalers and tablets and stuff and we're like, and he'll go: "I'm gonna shove it up my nose, I'm gonna shove it down my throat," and then he'll go and we'll go: "Ok, are you ready?" And then you try to carry it on without like, rising...

E: Giving him positive feedback, like saying: "Ah but you're doing so well with them and the doctor's really pleased."

Int: So one of the ways he'll self-harm is by obstructing taking his medication? So, how often does he do that? Is that a daily occurrence or...?

D: It can be. It depends. Sometimes with new staff, he'll try it on with them.

T: And the general mood of the house.

D: And he has actually sometimes tipped his medication into his tea...

S: But again, that was a new member of staff and he wanted a response, so...

T: If he knows he's not gonna get a response, he tends not to do it.

Int: So medication is one way. What else does he do?

E: Kicking things, injure his foot. It used to be regularly but now not quite so much, he'd kick things in order to hurt himself: his bed, he'll walk into, you'll see him bang against table legs or doors.

Int: Barefoot, presumably?

S: Yes. Or just with his slippers on. But...

P: Or he'll bang his hand on a cupboard door, he's hit his forehead on the corner of a door. He did that on the bathroom door when I first started (working) here.

E: Punch things, tears his clothes, T-shirts.

T: Gives himself friction burns with a towel.

S: Yeah...

T: On his shins. I think I've seen him do that twice.

Int: Gosh, I wasn't aware of that. This is when he's drying himself...

S: No, just when he, 'cause he wants to go to get medical attention. Or to make it so he has that as part of an interaction.

E: Yeah, he repeats it. He's even broken his wrist by banging it against a wall when it was starting to heal. When the cast is coming off, he'll re-break it.

Int: I see...

P: It's happened 3 times...

E: And they just stopped putting a cast on in the end, didn't they? They just said there was no point. They put a bandage thing on instead to alleviate the need for him to return and get a new cast.

S: But we also put things in place so that so, he was going off, going to his appointment and having his lunch out and having a bit of a day of it. And then he was choosing what colour cast he had and he was like, he now goes to his appointment and comes home, has his lunch and then go out on an activity after. So it disconnects the purpose so he doesn't get mixed messages.

E: And we weren't feeding into that whole: "Oh you've got a new cast" business...we don't interact with all that.

D: But did people used to sign his cast as well?

S: That was the first one. But not after that. It was then trying to...how we respond to that, so… yeah… and he will say certain things that he's, he'll be limping and be saying his foot hurts and stuff, so whenever he's in eye-shot, so if you're walking down the street, he'll walk along fine. Soon as he sees someone on the other side, he'll start limping, um, because he gets that feedback from other people so that, which we don't have control of to a degree.

Int: So the main ways in which he self-harms are medication, sort of punching and hitting parts of his body, his arms, breaking...

S: Yeah, he'll break things...

Int: Do you mean by throwing them?

D: Yeah, or snapping them...

Int: Does he then harm himself with....

S: He can. But it's a way of him escalating himself. So, he'll break it and he'll go: "That's your bloody fault, that is," and then you'll comment and you'll go:"Well, it is a shame that it's broken" and he'll like pick something up and he'll like, he's used a plug

to whack his head or stuff, before he wraps the cable round the lead of the stereo and he'll pull it tight or, you know, and he'll be looking at you intensely to try and to see what you're gonna do about that.

Int: OK.

E: The more you sort of....

S: He's pulled out his curtains. Erm...that kind of thing.

Int: So he's got quite a broad range (P: broad range, yeah...) of ways that he can damage himself.

S: Yeah.

Int: OK. So during the last 4 weeks, I mean you might not be able to give me a detailed number of incidents, but can you give me some idea how often he's deliberately harming himself in the last month?

S: I'll get the behaviour forms out of the cupboard...

E: As I say we've got the definite...

E: Yeah, the glass was a definite one. And actually, even after he'd had it bandaged,… um… and the bandage came off, he… because I,had to change it and he was like: "You can't do it, a nurse has to do it," and S. was like, "Well E. used to be a first-aider, so she's more than capable of doing it. She spent years in the Red Cross, St John's Ambulance..." And I was like: "Yeah, I'm more than capable of cutting it off and actually, it's not too bad, we'll just let it breathe." And he's like: "No, no it needs a bandage on it." And I'm saying: "No, you'll be fine. It's good that it can breathe. And it says in your notes, the nurse says, to only put plasters on if needed." So I put a plaster on a just a couple of bits that were gouged, but everything else is left. A few

hours later he came back and he'd clearly been, sort of, picking and making it a bit worse. And I just said: "Well, if we rinse them and then go back to bed, they'll be dried in the morning," so I sort of stood my ground and didn't give him any more plasters, because I thought he'd just want more and more and more.

D: You could wipe it with surgical spirit.

E: No,that wouldn't be very nice, that would be abusive. TCP, my Dad used to do.

D:And we'd go "Ah,bugger" "Yeah I ain't gonna do that again"

S: Um, so, if we go from the 30th of November, yeah.

Int: Yes, OK, that's fine.

S: Um, that was the bread incident. So, he thought it was cake and then he hit his arm in the door cupboard. (To colleague – That was your fault)

E: It was...

S: That was the smoke detector. Smashed his hand on the frame. Another one, that was about the sweets.

T: That wasn't self-harm though was it?

S: No, but it was still pushing with his behaviours.

E: So that's two notable incidents but he has complaining about his foot so you don't quite know.

Int: So is it possible that he is harming himself, perhaps in a less dramatic way when he is upstairs in his room and nobody's around, and what you hear is the: "My foot's hurting"?

S: And I think it's our reaction because we don't rise to that as such and so he'll come down and he'll say: "Oh I've hurt my foot" and we'll say: "Well you know what the nurse said about that" and he'll say:"I need to go back" and I was like :"They said that we need to rest it, pop it up on the side and we'll use the cold pack." He's like: "I need one of them" and I'm like:"They said that doesn't help, it just makes it worse. So they said to do this." So then it doesn't ever...

E: And they diagnose him with the onset of arthritis for his aches and pains, 'cause he kept complaining about it. So we did take him to the doctors to get it checked out. And the doctor said: "Ah well, you know, it's age and everything, and possibly arthritis and there's nothing we can do about that." Which does alleviate his need for...

S: Whenever we attend the hospital and stuff, the staff know. They look and they go "Oh yeah, D, you tend to hurt yourself on purpose," so they kind of say, and he's like: "Urgh...dammit, why does everybody know", sort of thing so he doesn't kind of get the reaction that he wants but that's down to us saying, you know, um, so if it's me and I've been with him in the past, I'd take them to one side and I'd go: "What he wants you to do is put a bandage on it" and then they go: "Right", and then they'll be like because he wants to be able to physically, so people can physically see something so it triggers, and then he can go:"Yeah, yeah, I hurt my foot" whatever, and so then they go: "Right, so we won't be putting anything on it" (laughs) and he's like: "And I need..." and they're like: "No, you don't need one of those. All you need to do is..." They obviously check it all out and stuff as well.